Conceptualización y Evaluación de la Gobernanza para la Salud de la Población Gitana en España

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Conceptualization and Evaluation of Governance for Roma Health in Spain

Executive Summary

Introduction

Roma health inequities in Europe and Spain as result of a secular discrimination. Despite being Europe's largest ethnic minority—Spain is the Western European country with the highest national and foreign Roma population—Roma across the continent have worse health than that of the rest of population regardless their socioeconomic status. They suffer earlier mortality and lower life expectancy; worse hearing, visual and mental health; more chronic and infectious diseases; worse self-perception of health; more traffic accidents, and less healthy behaviors than non-Roma populations. Women have more unplanned and teenage pregnancies, abortions and sexually transmitted diseases, while children suffer more premature births, asthma, malnutrition, domestic accidents, obesity, worse oral health and lower vaccinations. This appalling situation comes from a secular and systemic discrimination—which especially affects women, children and foreign Roma—reflected in antigypsy discourses, racism within healthcare systems, higher school failure and unemployment levels, and housing segregation.

The challenges of European and Spanish Roma health policies. Spain approved its first Roma Development Program in 1989 while the first European commitment was in 2005 with the Decade of Roma Inclusion—which Spain joined four years later. Since the unjust situation of the Roma persisted, the European Commission made it a priority under Europe

2020's agenda—as did the World Health Organization's Health 2020. Also, State Members were urged to develop National Roma Integration Strategies in the field of health to ensure coverage and access, impact the most vulnerable groups, and include professional Roma in programs by reinforcing policies, supporting authorities, and building stakeholder networks.

These policies involve challenges that hinder their impact (e.g., the low commitment of politicians, the gap between planning and implementation, or the weak inclusion in local policies). Critical voices alert that these policies might be promoting assistance, depoliticizing the real causes of inequities and racializing health problems. Others state that these have ceded decision-making spaces to bureaucratic non-Roma actors and Roma participation has been tokenized, manipulated and even co-opted by unsuccessful representatives. Policies are also based on non-representative research which have made Roma inequities invisible and neglected, impeding policy design, implementation and evaluation.

Addressing Roma health policy challenges by strengthening governance for health. *Governance for health* is proposed as the framework from which to develop the needed changes during the evaluation and redefinition of Roma health policies to ensure their impact. The Lancet–University of Oslo Commission on Global Governance for Health defines it as the processes aimed at assessing and overcoming the asymmetrical distribution of power and economic, intellectual, normative and political resources that negatively affect health. The values and perspective of community psychology can shed light to this process. From this approach, governance for Roma health demands (a) a new conceptualization of the problem in order to respond to its complexities; (b) new evaluation and accountability mechanisms; (c) the

identification of strengths and limitations to make policies more just, equitable and efficient; and (d) power reorganization by including new actors and roles;

This thesis aims to evaluate the implementation of the health branch of the National Roma Integration Strategy in Spain and other national commitments from the conceptual and methodological frameworks of governance for health. The following research objectives are proposed:

1. To develop a framework to assess and redefine policies that ensure governance for Roma health.
2. To design an assessment tool of governance for Roma health.
3. To identify good professional practices that ensure governance for Roma health at local level.
4. To redefine the role of stakeholders as capacity-builders of governance for Roma health.

Results

Results are presented following the objectives and their corresponding publications. The report 'Implementation of the National Roma Integration Strategy and other national commitments in the field of health – Spain. A multi-stakeholder perspective report on 2005-2014 developments' (Garcia-Ramirez, Escobar-Ballesta & Lizana, 2015; Appendix A) responds to the first objective aimed at developing a framework to assess and redefine Roma health policies from a wicked problem and a transformative policy change perspectives that relies on multistakeholder narratives and best available evidences. The paper 'Taking stock of Roma

health policies in Spain: lessons for health governance' (Escobar-Ballesta, Garcia-Ramirez & De Freitas, 2018; Appendix B) responds to the objective of designing and implementing a tool—the Roma Health Integration Policy Index—to assess governance for Roma health by identifying policy strengths and weaknesses regarding entitlement, accessibility, responsiveness and capacity to achieve and sustain changes. The paper 'Sexual and reproductive health in Roma women: the family planning programme of Polígono Sur in Seville (Spain)' (Escobar-Ballesta, Garcia-Ramirez, Albar & Paloma, 2018; Appendix C) relates to the third objective of identifying good professional practices that neutralize the low impact of policies by adjusting programs and services, and ensuring governance for Roma health at local level. Lastly, the paper 'The challenge of equity in health policies aimed at the Roma population in Spain' (Garcia-Ramirez, Escobar-Ballesta, Lizana & Albar, 2016; Appendix D) responds to the objective of redefining the role of stakeholders as capacity-builders of governance for Roma health through our experience as community psychologists during the evaluation of the implementation of the National Roma Integration Strategy's health branch, and the need for other stakeholders to embrace this role.

Discussion

From a wicked problem and transformative policy change perspective, this thesis has developed a framework and a tool to assess and redefine Roma health policies. Our results are consistent with other evaluations of the Decade of Roma Inclusion and the National Roma Integration Strategies, thus stating their limited impact in overcoming Roma health inequities. This has led to provide lessons from our experience to conceptualize effective, sensitive and just policies that ensure Roma health governance which might be useful in similar contexts.

Governance for Roma health needs intersectional and intersectoral approaches as well as the inclusion of health-related priorities in other sectoral policies. Our study has proven the success of the intersectional approach by adapting policies to the multiple vulnerabilities of users (e.g., Roma, women, poor, in at-risk contexts, low educational level) rather than prioritizing one over the others. This approach implies an intersectoral work of effective collaboration between the health sector and other axes that determine health (e.g., education, housing, social services) so policies are planned considering their effect on Roma health.

Governance for Roma health needs Roma transformative participation. Our study highlights the need for the real and effective participation of Roma, especially the most silenced ranks—to challenge the dominant discourses during policy design and implementation that have been frequently tokenized and lacking legitimate Roma representation. This participation can propel empowering settings in which the Roma exert direct influence at community and policy levels by prompting fairer, more sensitive and effective policies.

Governance for Roma health needs new stakeholder roles. Our study has highlighted the role of community psychologists as capacity builders of governance for Roma health during the policy evaluation process. This role can be extended to other stakeholders who act as mediators, instigators and advocators of Roma health within their organizations by redefining policies, reallocating resources to ensure governance and dismantling institutional discrimination. Roma must become advocators of their own health within their communities and

institutions, with power and opportunities to lead changes in the design, implementation and evaluation of policies that affect them.

Governance for Roma health needs accountability mechanisms to ensure visibility, transparency and responsibility. Our study has highlighted the importance of using adjusted approaches and tools to assess Roma health policies that present challenges during their design and implementation. This allows identifying policy strengths and limitations in order to redefine them according to the needs of Roma and the context in which they are applied, as well as to strengthening evidence-base with good practices in policymaking. Evaluation should be emphasized at local levels through stakeholder coalitions that include Roma health advocators. This will allow ensuring transparency, accountability and co-responsibility throughout the governance process.

Among the limitations, this study was only implemented in two Spanish autonomous regions and mainly focused on national Roma. Also, it serves to evaluate the causes of policy failure but does not evaluate particular cases. Our study on good practices focused on a well-known Roma health problem (i.e., sexual and reproductive health) rather than other important and neglected ones (e.g, vision and hearing health). Lastly, the study fails to ensure Roma's real voices without relying on organizational intermediaries.

In conclusion, this thesis has highlighted the need to strengthen governance for Roma health through transformative policy design and evaluation committed to the values of social justice, equity and human rights that facilitate Roma health, wellbeing, and thriving.

Prefacio

Europa afronta el desafío de desarrollar e implementar políticas de salud efectivas para la población gitana. Ésta fue una meta de la iniciativa COST "ADAPT: Adapting European health systems to diversity*"* (COST, 2011), la cual me permitió acercarme por primera vez a este desafío a través de una Short Term Scientific Mission en el Norwegian Center for Migration and Minority Health (NAKMI) en Oslo. Esta experiencia, reflejada en el artículo "Liberating narratives against gender-based violence in a community of Pakistani women in Norway" (Aambø, Escobar-Ballesta & Garcia-Ramirez, 2017), me permitió aprender que las políticas diseñadas e implementadas por agentes alejados de las comunidades pueden resultar ineficaces, silenciar a las poblaciones a las que se dirigen y perpetuar en ellas los problemas que tratan de superar. Esta lección me enseñó la necesidad de incorporar en las bases conceptuales y metodológicas de las políticas de salud dirigidas a minorías étnicas la perspectiva de todos los agentes involucrados y reforzar el papel de las poblaciones en su diseño e implementación.

La población gitana es la minoría más numerosa, pobre y con peor estado de salud de Europa. Muchos gobiernos e instituciones europeos han expresado su preocupación por la ineficacia de las iniciativas que se han emprendido para hacer frente a esta situación. La International Organization for Migration desarrolló, entre 2013 y 2016, el proyecto "Equi-Health: Fostering health provision for migrants, the Roma and other vulnerable groups" con el fin de monitorizar los avances en salud de las acciones realizadas en el marco de las Estrategias

Nacionales para la Inclusión de la Población Gitana (en inglés, National Roma Integration Strategies), detectar errores y explorar posibles palancas de cambio (IOM, 2013). CESPYD, el Centro de Investigación y Acción Comunitaria de la Universidad de Sevilla—al que pertenezco desde 2011, fue el consultor nacional encargado de elaborar el informe de progreso de la implementación en España de la rama de salud de dicha estrategia en colaboración con la Agència de Salut Pública de la Generalitat de Catalunya. Fue aquí donde encontré el escenario para realizar mi tesis doctoral, proyectando las inquietudes que había desarrollado en mi trabajo en NAKMI. El punto de partida de mi trabajo sería constatar si el compromiso formal de las instituciones para superar las inequidades que sufre la población gitana relacionadas con su salud estaba plasmándose en políticas y acciones efectivas, cómo lo estaban logrando y qué mecanismos de cambio podían ser desarrollados para corregir errores y asegurar la sostenibilidad de los logros. Con este fin, mi trabajo de tesis doctoral ha tratado de dar respuesta a la siguiente pregunta: ¿están las nuevas políticas europeas respondiendo de manera efectiva, sensible y sostenible a las condiciones de inequidad que sufre la salud de la población gitana en España?

Términos de la Investigación y Consideraciones de Interpretación

Este trabajo se centra en algunos conceptos fundamentales que deben ser aclarados: población gitana, políticas e inequidades en salud. Considerando el contexto europeo y la movilidad de su población, se hace distinción entre población gitana nacional y extranjera. La primera se refiere a aquella que nace y reside en España, la segunda a aquella que nace y vive en otros países europeos—principalmente del centro y este de Europa—o que emigran a España desde estos. El término "población gitana" es utilizado para referirse indistintamente a ambos

grupos. Los adjetivos "gitano/a" son usados para aludir a elementos o características de esta población. Se ha intentado ser consistente en la utilización de esta terminología tanto en inglés como en español. No obstante, cualquier variación ha sido aclarada en el propio texto (e.g., "*traveler*" aparece para denotar a población gitana extranjera con altos niveles de movilidad). Todos estos términos se adecúan a los recomendados por el Consejo de Europa para referirse a esta población (Council of Europe, 2012a).

El término "política" se emplea en este trabajo como la traducción literal del inglés "*policy.*" La World Health Organization define "políticas de salud" como las decisiones, planes y acciones que se llevan a cabo para lograr objetivos específicos de salud en una sociedad (WHO, 2018a). Estas políticas surgen de la interacción de diferentes agentes a múltiples niveles (e.g., gubernamental, comunitario, organizacional) (Ingleby, 2012). Así, "políticas" se emplea para referirse a las leyes, estrategias, planes y programas encaminados a mejorar la salud de la población gitana. Las "prácticas" son la implementación y traducción de estas políticas en acciones que permiten conseguir los objetivos planteados. Esta tesis se centra en políticas de salud dirigidas a población gitana en España, siendo éstas principalmente la Estrategia Nacional de Inclusión de Población Gitana y otros compromisos adoptados por los gobiernos nacionales y regionales para abordar los problemas e inequidades en salud de la esta población.

Esta tesis utiliza la definición de la World Health Organization que entiende las inequidades en salud como las diferencias en el estado de salud entre poblaciones debido a las condiciones en las que nacen, crecen, viven, trabajan y envejecen. Estas condiciones están determinadas por la distribución desigual del dinero, el poder y los recursos, lo que hace que las

inequidades en salud sean injustas y evitables (WHO, 2017). Es responsabilidad de los gobiernos y de todos los agentes implicados eliminar estas inequidades y asegurar la salud de las poblaciones independientemente de su raza o condición económica o social (WHO, 2018b).

Por último, esta tesis sigue las recomendaciones de la Real Academia Española para el abordaje de las cuestiones de género, proponiendo el uso del masculino genérico en su condición de término no marcado en la oposición masculino/femenino. Esta decisión se ha tomado en virtud de la economía expresiva, sin ninguna intención de tipo discriminatorio.

Estructura de la Tesis

Esta tesis doctoral ha sido desarrollada a través de un compendio de publicaciones y se presenta a lo largo de tres capítulos: Introducción, Resultados y Discusión (Boletín Oficial de la Universidad de Sevilla, 2012). La Introducción contextualiza y justifica el problema de investigación y expone los objetivos de la tesis doctoral. La literatura utilizada en este primer capítulo data hasta 2014, año en el que planteo los objetivos y realizo la principal recogida de datos. El Capítulo 2 presenta los resultados de investigación a través de los trabajos publicados: un informe científico-técnico y tres artículos científicos. Estas publicaciones pueden ser leídas de manera independiente; aunque comparten marco teórico, metodológico y, en ocasiones, resultados, cada publicación representa un trabajo original que acerca el proceso de investigación a la consecución de los objetivos propuestos. Finalmente, el Capítulo 3 presenta una discusión de las principales aportaciones de este trabajo de investigación en función de la literatura existente actualizada, además de sus limitaciones y una conclusión final.

Tabla de Contenidos

Índice de Abreviaturas y Acrónimos

CCAA	Comunidades Autónomas
CS	Centro de Salud
EC	European Commission
ENIPG	Estrategia/s Nacional/es para la Inclusión de la Población Gitana
ENIPG-S	Rama de salud de la Estrategia Nacional para la Inclusión de la Población Gitana
FRA	Fundamental Rights Agency
FSG	Fundación Secretariado Gitano
IOM	International Organization for Migration
MSSSI	Ministerio de Sanidad, Servicios Sociales e Igualdad
PG	Población gitana
RHIPEX	Roma Health Integration Policy Index
SNS	Sistema/s nacional/es de salud
UE	Unión Europea
WHO	World Health Organization

Capítulo 1

Introducción

En este capítulo expondré que el bajo impacto de las políticas de salud en la población gitana (PG) tiene el mismo origen que los problemas de salud que sufre y las injustas condiciones de vida que soporta. La discriminación sufrida por la PG ha generado un círculo vicioso que mantiene la brecha en salud que la separa del resto de la población y fagocita cualquier iniciativa que trate de superarla. Por tanto, sostenemos que el marco conceptual y metodológico que debe inspirar las políticas europeas actuales debe estar dirigido a combatir las inequidades de la PG a partir de la promoción de estructuras que aseguren la gobernanza para su salud.

Las Inequidades en Salud de la Población Gitana en Europa y España como Resultado de una Secular Discriminación

Desde su llegada a Europa desde el norte de India entre los siglos IX y XIV, la historia de la PG ha estado continuamente marcada por la persecución y el ostracismo; huyendo de la esclavitud, del genocidio, de ataques racistas, y de leyes que castigaban sus tradiciones y forma de vida (Cahn & Guild, 2010; Hajioff & McKee, 2000; Parekh & Rose, 2011; Ringold, Orenstein & Wilkens, 2005; Strochlic, 2011). En España, la PG ha sobrevivido desde el siglo XV entre la aceptación y el rechazo. En un país predominantemente católico, muchos fueron obligados a asimilar la cultura y religión de la mayoría o ser expulsados. Otros decidieron vivir escondidos para mantener sus tradiciones, subsistiendo en la mendicidad y aprovechando la

paradójica fascinación que la sociedad mayoritaria sentía por sus costumbres y sus habilidades para los negocios y las artes (Fundacion Secretariado Gitano [FSG], 2013a; Gamella, 2007; La Parra, Gil-González & Jiménez, 2013; Ringold, Orenstein & Wilkens, 2005). No fue hasta 1978, con la restauración de la Democracia, que la PG quedaba amparada por la Constitución, reconociendo sus derechos y prohibiendo cualquier discriminación debido a la etnia (FSG, 2006; Ringold, Orenstein & Wilkens, 2005).

A día de hoy, la PG constituye la minoría étnica más grande de Europa; entre 12 y 15 millones viven en el continente y alrededor de 10 millones se encuentran repartidos por la Unión Europea (UE; European Union, 2008). Mientras que Rumanía es el país con mayor número de PG nacional en el este de Europa, España destaca por serlo en el occidente (Ringold, Orenstein & Wilkens, 2005). Las últimas encuestas sitúan a la PG entre 725.000 y 1,5 millones de personas; aproximadamente, el 40% de la PG vive en Andalucía, seguida de Cataluña, Madrid y Valencia (Damonti & Arza, 2014; Laparra, 2011). A pesar de estas cifras, la PG no está oficialmente reconocida como una minoría étnica nacional (FSG, 2006). Además, junto con Bélgica, Francia e Italia, España cuenta con una importante PG extranjera procedente de Bulgaria y Rumanía que, debido a la ampliación de la UE en la última década, han decidido buscar mejores condiciones de vida fuera de sus países de origen (Cahn & Guild, 2010; Gamella, 2007; McKee, Balabanova & Steriu, 2007; Ringold, Orenstein & Wilkens, 2005).

En general, la PG es un grupo heterogéneo en el que múltiples factores (e.g., religión, oficio, uso de la lengua romaní, tradiciones y prácticas, etc.) la caracterizan como una minoría étnica única y diversa (Laparra, 2007, 2011; Ringold, Orenstein & Wilkens, 2005). No obstante,

la PG también comparte fortalezas independientemente de su lugar de origen o residencia. Ésta tiene una gran capacidad de crecimiento: cuenta con una población muy joven y escasa población anciana (FSG, 2009; Laparra, 2011). Mientras que el hombre es tradicionalmente la figura de autoridad en los espacios públicos, la mujer es esencial para garantizar los cuidados y preservar la continuidad del linaje, sus valores y costumbres (Dimitrova, Chasiotis, Bender & Van de Vijver, 2014; FSG, 2012a; Vincze, 2006, 2014). La familia es el espacio determinante para la socialización y el desarrollo psicológico de sus miembros, donde construyen una identidad colectiva resistente y una fuerte cohesión social con la que hacer frente a la discriminación y estigmatización que sufren secularmente (Dimitrova et al., 2014; Lee, Keyes, Bitfoi, Mihova, Pez et al., 2014; Smith & Ruston, 2013).

Respecto a las inequidades en salud, se ha puesto de manifiesto cómo la salud de la PG en Europa es peor que la del resto de población independientemente de su estatus social (Foldes & Covaci, 2012; La Parra, 2009). En España, diversos estudios avalan esta situación y evidencian los problemas de salud que sufre la PG (Cabedo, Ortells i Ros, Baquero, Bosch, Montero et al., 2000; Ferrer, 2003; La Parra, 2009; Laparra, 2007; Ministerio de Sanidad y Consumo & FSG [MSC-FSG], 2005). Aunque la mayoría de estos trabajos no incluyen datos sobre PG extranjera, estudios realizados en Cataluña muestran que su estado de salud es peor que el de la PG nacional y comparable al de la PG en sus países de origen (López & Sáez, 2009; Méndez, 2011). Se cree que, en general, el estado de salud de la PG es mejor en España que en países centroeuropeos debido al mayor desarrollo económico y a la implementación de políticas destinadas a mejorar la calidad de vida de la población general en los últimos años (e.g., asistencia sanitaria universal, rehabilitación de las zonas marginales, ampliación de la escolarización obligatoria) (FSG, 2012b;

Laparra et al, 2011; Maya & Mirga, 2009; Ringold, Orenstein & Wilkens, 2005). No obstante, la literatura muestra que la PG a lo largo de toda Europa comparte similares problemas de salud.

La PG presenta mayores índices de mortalidad temprana y menor esperanza de vida al nacer que el resto de la población (Cook, Wayne, Valentine, Lessios & Yeh, 2013; Ferrer, 2003; La Parra, 2009; MATRIX, 2014; Parekh & Rose, 2011). Padece peor salud auditiva y visual y mayor número de enfermedades crónicas no transmisibles (e.g., cardiovasculares, colesterol, diabetes, jaquecas, hipertensión, artrosis y obesidad) e infecciosas (e.g., tuberculosis, hepatitis) (Cook et al., 2013; Ferrer, 2003; Hajioff & McKee, 2000; La Parra, 2009; MATRIX, 2014; MSC-FSG, 2005; Parekh & Rose, 2011). También se ha observado una peor autopercepción de su salud, mayor número de accidentes de tráfico y menos conductas saludables (e.g., sedentarismo, consumo de alcohol, tabaco y otras drogas) (Ferrer, 2003; Hajioff & McKee, 2000; La Parra, 2009; MATRIX, 2014; MSC-FSG, 2005; Parekh & Rose, 2011). En cuanto a salud mental, la PG presenta mayores niveles de estrés, depresión, ansiedad y baja autoestima, especialmente en mujeres (Cook et al., 2013; La Parra, 2009; Lee et al., 2014; Parekh & Rose, 2011). Éstas, además, tienen problemas de salud sexual y reproductiva específicos como altas tasas de embarazos no planificados, embarazos en edad adolescente de riesgo para la madre y el bebé, abortos, e infecciones de transmisión sexual (Carrasco, López de Andrés, Hernández, Jiménez & Jiménez, 2010; Ferrer, 2003; Fundamental Rights Agency [FRA], 2013; Hajioff & McKee, 2000; La Parra, 2009; Mihailov, 2012; MSC-FSG, 2005; Vincze, 2006). Por otro lado, la población infantil sufre mayor número de nacimientos prematuros, mayores tasas de mortalidad, asma, malnutrición, accidentes domésticos y obesidad, peor salud bucodental y menor tasa de vacunaciones (Cook et al., 2013; Ferrer, 2003; FSG, 2009; Hajioff & McKee,

2000; La Parra, 2009; MATRIX, 2014; Mihailov, 2012; MSC-FSG, 2005; Parekh & Rose, 2011).

Estos problemas de salud vienen determinados por una discriminación sistémica que sitúa a la PG como el grupo más rechazado de Europa y que la condena a injustas condiciones de vida en múltiples ámbitos (e.g., social, educativo, laboral, vivienda, sanidad). A nivel social, algunos países de la UE (e.g., Francia, Italia, Hungría) han adoptado en los últimos años discursos antigitanos que respaldan su expulsión y/o segregación, aumentando el número de crímenes por odio racial, identificaciones y abusos policiales (Council of Europe, 2012b; FRA, 2009a; Human Rights First, 2008). Algunos medios de comunicación, cómplices de estos discursos, proyectan en el imaginario colectivo una visión negativa y estereotipada de la PG (e.g., conflictivos, ladrones, vagos) que, exacerbada por la crisis económica, la culpabiliza de su propia situación así como de otros problemas sociales (e.g., monopolización de ayudas sociales, robos, incivismo) (Cahn & Guild, 2010; FSG, 2013ab; Human Rights First, 2008; Laparra, 2011; Strochlic, 2011).

En los sistemas nacionales de salud (SNS) también se observan prejuicios y actitudes racistas por parte de profesionales, se excluye a la PG de campañas y programas de prevención y promoción de la salud, los servicios y protocolos no están culturalmente adaptados e, incluso, se les niega el derecho y acceso a la salud (Janevic, Sripad, Bradley & Dimitrievska, 2011; La Parra, Gil-González & Jiménez, 2013). Esta discriminación aumenta el miedo y desconfianza de la PG hacia las instituciones que deben velar por su bienestar y obstaculiza el acceso y disfrute de servicios de calidad, haciendo que acceda de manera tardía a programas preventivos y use la atención sanitaria urgente (FRA, 2003; FSG, 2009; Janevic et al., 2011; Smith & Ruston, 2013).

Por otra parte, también hay que señalar las inequidades presentes en los determinantes sociales de la salud de esta población. A nivel educativo, la discriminación hacia la PG se refleja en altas tasas de fracaso escolar, analfabetismo y un techo formativo que culmina en el abandono de la educación (Brüggeman, 2012; Laparra, 2011). Mientras que las cifras de abandono escolar para el resto de la población es del 19,4% en España y un 14,9 % para la media europea, para la PG nacional asciende al 63,4% (FSG, 2013c). A nivel laboral, la discriminación se traduce en altas tasas de desempleo: en España, en comparación con el 20,9% del resto de la población, el 36,4% de la PG nacional está desempleada, siendo la cifra para población extranjera muy similar (FSG, 2012a). La PG que logra acceder a puestos de empleo lo hace en subempleos, en trabajos que nadie quiere, de alto riesgo, sin seguridad social o en la economía sumergida (FRA, 2014a; Council of Europe, 2012b). Así, la PG es la minoría étnica más pobre de Europa—hasta diez veces más pobre que el resto de la población (Ringold, Orenstein & Wilkens, 2005). En 2013, el 33,3% de PG en España se encontraba en situación de pobreza moderada y el 37,8% sufría pobreza severa en comparación con, respectivamente, el 20,6% y 6,5% del resto de la población (Damonti & Arza, 2014). Esta situación empeora para la PG extranjera en España y en sus países de origen (FRA, 2014a). La PG también vive espacialmente segregada, en guetos con chabolismo vertical, en condiciones insalubres y con limitado acceso a servicios. La PG extranjera tiene mayor probabilidad de vivir en chabolas donde replican las condiciones de vida de sus países, o en la calle, debido a los desalojos forzosos de los asentamientos por parte de las autoridades (Laparra, 2011; FRA, 2009b; FSG, 2008).

Como vemos, esta discriminación secular tiene mayor impacto en los grupos más vulnerables de la comunidad gitana, tales como la población extranjera, los menores y las

mujeres. Especialmente, las mujeres y niñas gitanas sufren los roles y mandatos de género de la sociedad patriarcal en general y de la comunidad gitana en particular. Esto las empuja a asumir desde muy jóvenes el rol de cuidadoras que las condena al abandono precoz de la escuela, al subempleo y a la dependencia económica, y las hace más vulnerables a sufrir violencia doméstica (Cukrowska & Kóczé, 2013; FRA, 2003, 2014b; FSG, 2012c; Vincze, 2006). Casi el 2% de las niñas gitanas en Europa entre 10 y 15 años están casadas o cohabitan con su pareja; y solo el 6% de madres adolescentes completa los estudios primarios, dedicándose la mayoría a tareas del hogar (FRA, 2013). Todas estas manifestaciones son una evidencia de cómo la discriminación que sufre la PG determina sus condiciones de vida y su estado de salud.

Los Desafíos de las Políticas de Salud Dirigidas a Población Gitana en Europa y España

Aunque los problemas de salud de la PG no es un asunto sobrevenido, no ha sido hasta hace menos de quince años cuando se ha emprendido voluntad política en Europa y sus estados miembros para hacerles frente (Figura 1).

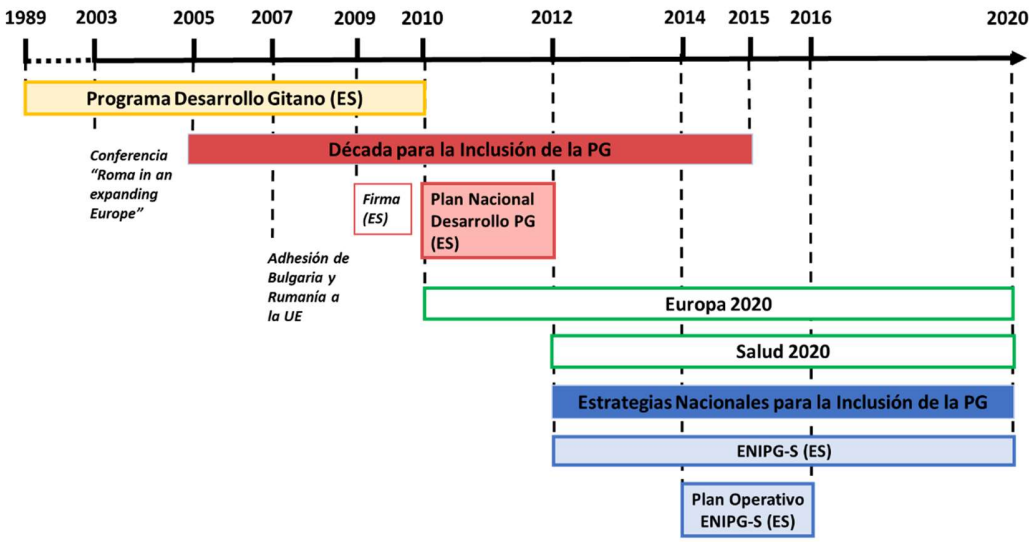

Figura 1. Políticas de salud dirigidas a población gitana en España y Europa

En España, los primeros esfuerzos se remontan al año 1989, una década después de la restauración de la Democracia. El Programa de Desarrollo Gitano promovía la colaboración entre gobiernos nacionales, regionales y locales, el apoyo e inclusión del asociacionismo gitano en las instituciones, la sensibilización sobre la situación y cultura de la PG y la capacitación de profesionales (Villareal, 2001). Además de contar con un presupuesto estable de la Administración General del Estado y los distintos gobiernos, el programa también disponía de organismos específicos de asistencia técnica y administrativa. Entre sus limitaciones destacaba, sin embargo, la falta de una estrategia clara y pública, la baja participación del gobierno y coordinación interdepartamental, el escaso diálogo con las asociaciones, y al hecho de que las evaluaciones fueran únicamente en relación a gastos y al tipo de actividades financiadas (Villareal, 2001).

No fue hasta la inminente inclusión en la UE de Rumanía y Bulgaria—países con gran proporción de PG—y la libre circulación de personas dentro del espacio Schengen, que los gobiernos se vieron obligados a encontrar la forma de integrar una población extensa, culturalmente diferenciada y pobre en una UE democrática y abierta pero con unos valores y estilos de vida determinados (McKee, Balabanova & Steriu, 2007; Vincze, 2014). Con esta preocupación, en 2003, se celebra en Budapest la conferencia "Roma in an Expanding Europe: Challenges for the Future" organizada y cofinanciada por el World Bank, el Open Society Institute y la European Commission (EC; Ringold, Orenstein & Wilkens, 2005). Con más de 500 asistentes de 30 países—entre los que se incluían líderes de la PG, el objetivo era evidenciar las injustas condiciones socioeconómicas de esta población, intercambiar experiencias, planificar acciones y promover la cooperación. Como resultado se firmó la Década para la Inclusión de la

PG 2005-2015 (en inglés, Decade of Roma Inclusion), el primer acuerdo político para combatir la pobreza, exclusión y discriminación en los ámbitos de la salud, empleo, educación y vivienda, promover la igualdad de género y la participación de la PG, así como monitorizar sus avances (Decade of Roma Inclusion, 2005). La Década aunaba esfuerzos de gobiernos nacionales (i.e. Albania, Bosnia y Herzegovina, Bulgaria, Croacia, República Checa, Hungría, Macedonia, Montenegro, Rumanía, Serbia, Eslovaquia y España), organismos internacionales (i,e., World Bank, Open Society Institute, United Nations Development Program, Council of Europe) y la sociedad civil gitana. Todos se comprometieron a desarrollar, ajustar e implementar Planes Nacionales de Acción, financiar sus actividades, y asegurar mecanismos de participación para la PG. España elabora su correspondiente Plan de Acción Nacional para el Desarrollo de la PG en 2010, un año después de su incorporación a la Década. En salud se pretendía mejorar el acceso y uso de los servicios normalizando la relación entre la PG y el SNS, reducir la brecha en salud entre la PG y el resto de la población, y garantizar información sanitaria sobre PG y las actuaciones desarrolladas (Ministerio de Sanidad, Política Social e Igualdad, 2010). El plan fue diseñado por los diferentes Ministerios, gobiernos regionales y asociaciones gitanas del Consejo Estatal del Pueblo Gitano—organismo interministerial, consultivo y asesor que media entre las asociaciones y la Administración General del Estado. El presupuesto para el área de salud correspondía al 2,84% del total, el cual provenía de partidas generales del Estado para población vulnerable y específicas para PG de diversas fuentes (i.e., subvenciones a entidades gitanas, cofinanciación de las comunidades autónomas [CCAA], y Fondos Estructurales europeos) (Ministerio de Sanidad, Servicios Sociales e Igualdad [MSSSI], 2013). La evaluación final del plan—realizada por los mismos agentes que lo diseñaron e implementaron—destaca la falta de

fuentes de verificación e indicadores de evaluación, la débil coordinación entre gobiernos e instituciones, la descentralización administrativa y la ausencia de mecanismos de control de gastos y resultados (MSSSI, 2013).

Cinco años después del inicio de la Década, la EC prioriza la inclusión de la PG dentro de la estrategia Europa 2020—el marco de referencia para el crecimiento inteligente, sostenible e integrador de la UE—tras evidenciar la persistente e inaceptable situación de la PG (EC, 2010ab) Esto, junto con otros estudios, pusieron de manifiesto los desafíos de las políticas en salud dirigidas a PG para ser efectivas, entre ellas: el bajo apoyo, compromiso y liderazgo de los responsables; la brecha entre el diseño y la implementación; la dificultad de impactar en los sectores más vulnerables de la PG; la débil inclusión de las recomendaciones europeas a nivel regional y local; la escasa financiación, malversación de fondos y corrupción; la baja participación de la PG; la escasa evaluación e inexistencia de datos fiables; la débil difusión y sostenibilidad de los programas, así como el solapamiento de iniciativas (EC, 2010b; Fésüs, Piroska, McKee & Ádány, 2012; Foldes & Covaci, 2012; Parekh & Rose, 2011).

Ante esta situación, la WHO, dentro del marco Salud 2020, enfatiza el abordaje de las inequidades en salud de la PG a partir de la reducción de las desigualdades y el fortalecimiento de SNS centrados en las personas, universales, equitativos, sostenibles y de calidad (WHO, 2013). Previamente—y sin haber finalizado la Década—la EC moviliza a los estados miembros bajo el marco de las Estrategias Nacionales para la Inclusión de la PG (ENIPG; en inglés, National Roma Integration Strategies) desde 2012 hasta 2020 (EC, 2011). El objetivo es complementar y reforzar las políticas existentes desde una perspectiva gitana, apoyar a las

diferentes autoridades en su monitorización y diseminación, construir una red de diálogo y participación entre agentes claves, y desarrollar estrategias para abordar las inequidades de la PG en los principales determinantes sociales (i,e., salud, empleo, educación y vivienda). La rama en salud de las ENIPG (ENIPG-S) deben asegurar la cobertura y acceso de la PG a los servicios sanitarios (e.g., básicos, emergencia, especializados, prevención) en las mismas condiciones que el resto de la población, desarrollar acciones para los sectores más vulnerables (e.g., mujeres, niños, asentamientos) e incluir PG cualificada en los programas de salud (EC, 2012, 2013). En España, la ENIPG-S se basa en las políticas anteriores y otras vigentes (e.g., Estrategia Nacional de Equidad en Salud) y diferencia objetivos para población adulta e infantil (MSSSI, 2012). En adultos, estos se dirigen a mejorar la percepción de la salud, y reducir los accidentes de tráfico, el tabaquismo en hombres y la obesidad en mujeres, y el número de éstas que nunca han ido al ginecólogo. En menores, se pretende reducir el número de accidentes domésticos y la obesidad e incrementar la salud bucodental (MSSSI, 2012). Para ello se establecen líneas de acción estratégicas específicas relacionadas con la accesibilidad, uso y eficacia de los servicios sanitarios así como de cooperación administrativa y participación, y otras de carácter transversal (e.g., acción social, conocimiento disponible, género, PG extranjera). Al igual que en planes anteriores, la financiación de la ENIPG-S proviene de partidas presupuestarias generales y específicas. El MSSSI es el responsable de su planificación, seguimiento y evaluación, y cuenta con mecanismos de cooperación técnica en la Administración General del Estado, las CCAA y el Consejo Estatal del Pueblo Gitano. A pesar de que la publicación de la ENIPG-S fue en 2012, su implementación oficial no tuvo lugar hasta la divulgación del Plan Operativo en 2014 (MSSSI, 2014).

A día de hoy, el bajo impacto de las políticas de salud dirigidas a PG también se deriva del débil poder ejecutor de los organismos europeos que resultan en políticas discriminatorias. Mientras que su rol se limita a promover recomendaciones y directrices a los países en cuestiones de no discriminación y visibilizar las inequidades de la PG, la responsabilidad última recae en los gobiernos—muchas veces abiertamente racistas—y en sus interpretaciones de dichas recomendaciones (Fésüs et al., 2012; Parekh & Rose, 2011; Vincze, 2014). Estos gobiernos acaban desarrollando políticas neoliberales que desatienden los determinantes sociales de la salud, buscan curar en lugar de cuidar, distribuyen recursos en base a la igualdad en lugar de la equidad, reducen la inversión pública y eliminan la responsabilidad del estado sobre sus ciudadanos y sobre el fracaso de sus políticas (Beauchamp, 2010; Navarro, 2013; Nelson, 2013). Voces críticas alertan que el fin de estas políticas no es *integrar* a la PG sino *europeizarla* para convertirla en fuerza laboral, promoviendo el asistencialismo, *racializando* los problemas de salud y despolitizando sus causas reales, perpetuando así el ciclo de segregación e inequidad de (Fésüs et al., 2012; Vincze, 2014). Por otro lado, las políticas tienden a fracasar debido a que los espacios de participación y decisión durante su diseño, implementación y evaluación han sido tradicionalmente ocupados por personas ajenas a la comunidad gitana y con un perfil muy institucionalizado (e.g., planificadores/as, políticos/as, expertos/as). Generalmente, los proveedores de servicios socio-sanitarios responsables de implementar estas políticas a nivel local han sido relegados a una posición secundaria. Y cuando se ha querido incluir a la PG, ha sido de manera instrumentalizada y *tokenizada,* legitimando decisiones ya tomadas por expertos y/o a través de interlocutores que han cooptado la voz de la comunidad afirmando representar sus intereses a pesar de no ser reconocidos por ésta (EC, 2010; Maya & Mirga, 2014; Tremlett &

McGarry, 2013). Igualmente, la protección de datos relativos a la etnia—aun con la intención de protegerla—ocasiona la invisibilización y negligencia de los problemas e inequidades en salud de la PG. Así, las políticas se basan en estudios poco representativos, de muestras pequeñas, desactualizados, que refieren principalmente a PG en condiciones de exclusión, y que no disponen de sistemas de evaluación y monitorización fiables (Cook et al., 2013; EC, 2010; Fésüs et al., 2012; Foldes & Covaci, 2012; Hajioff & McKee, 2000; Open Society Foundations, 2010; Oprea, 2003; Parekh & Rose, 2011; Tremlett & McGarry, 2013). Esto se traduce en políticas desconectadas de las realidades y necesidades de la PG, con dificultades para ser implementadas y generar impacto, y que perpetúan la reproducción el ciclo de discriminación e inequidad. En definitiva, las dificultades de las actuales políticas de salud dirigidas a PG exigen nuevas formas de hacer políticas.

Combatiendo las Inequidades en Salud de la Población Gitana a partir del Fortalecimiento de la Gobernanza para su Salud

Las políticas de salud dirigidas a la PG necesitan cambios significativos durante su diseño, implementación y evaluación. La gobernanza para la salud se presenta como el marco desde el que desarrollar estos cambios. The Lancet–University of Oslo Commission on Global Governance for Health define "gobernanza para la salud" como los procesos encaminados a evaluar y superar la distribución asimétrica de poder y de los recursos económicos, intelectuales, normativos y políticos que afectan a la salud, limitan las oportunidades para su abordaje y desencadenan situaciones de injusticia y opresión (Ottersen, Dasgupta, Blouin, Buss, Chongsuvivatwong, et al., 2014). La gobernanza para la salud va más allá del "gobierno de la

salud," referido al uso de instituciones, normas y procesos formales e informales por parte de los estados, instituciones gubernamentales y actores no estatales para abordar los desafíos de la salud (Ottersen et al., 2014). La gobernanza permite desmantelar la discriminación presente en las políticas de salud y en las instituciones que las formulan y llevan a cabo, identificando dónde y cómo intervenir para desarrollar políticas más justas, sensibles y equitativas y mejorar la efectividad e influencia de sus resultados en la salud de la población (Griffith, Mason, Yonas, Eng, Jeffries, et al., 2007; Ottersen et al., 2014). El marco Salud 2020 de la WHO se basa en este concepto para abordar los nuevos y complejos desafíos del siglo XXI (e.g., obesidad, tabaquismo, salud mental) (Kickbusch, & Gleicher, 2012; WHO, 2013).

La gobernanza para la salud de la PG puede verse beneficiada a partir de las contribuciones de la psicología comunitaria en cuanto a valores y principios, tales como la equidad, la justicia y el cambio social, y el empoderamiento de los grupos más vulnerables (Bishop, Vicary, Browne, & Guard, 2009, Nelson, 2013). Desde su aparición en los años 60 y 70, esta disciplina ha estado presente en el ámbito de la formulación de políticas. Al fin y al cabo, uno de los objetivos de la psicología comunitaria es transformar realidades sociales, las cuales están conformadas por políticas públicas que, a su vez, están mediadas por comunidades e individuos (Bishop et al., 2009). En este sentido, la psicología comunitaria puede influir en la gobernanza para la salud en cuanto a que llama a la movilización crítica de la sociedad, guía la investigación y la acción hacia la consecución de los derechos en salud, y fomentar la toma de acciones para eliminar las inequidades injustas y evitables y desarrollar políticas encaminadas a generar cambios estructurales (Balcazar, Garate-Serafini & Keys, 2004; Bishop et al., 2009, Nelson, 2013).

Partiendo desde la perspectiva de la psicología comunitaria, fortalecer la gobernanza para la salud con el fin de combatir las inequidades en salud de la PG exige (a) desarrollar una nueva conceptualización del problema que incluya todas las perspectivas y sus complejidades (e.g., cuestiones de poder, perspectiva de múltiples agentes); (b) establecer nuevos procesos y mecanismos de evaluación y rendición de cuentas que sean iterativos y permitan *feedback*; (c) reorganizar el poder en los procesos a través de la inclusión de nuevos agentes y la asunción de nuevos roles entre todos los implicados; y (d) identificar las fortalezas de cada contexto para desarrollar políticas adaptativas y resilientes (Griffith et al., 2007; Kickbusch, & Gleicher, 2012; Nelson, 2013; Ottersen et al., 2014).

Esta tesis doctoral evalúa la implementación de la rama de salud de la Estrategia Nacional para la Inclusión de la Población Gitana en España y otros compromisos nacionales desde el marco conceptual y metodológico de gobernanza para la salud. Para ello se plantea los siguientes objetivos:

1. Desarrollar un marco de evaluación y redefinición de políticas para asegurar la gobernanza para la salud de la población gitana.
2. Diseñar una herramienta para evaluar la gobernanza para la salud de la población gitana.
3. Identificar buenas prácticas profesionales que aseguren la gobernanza para la salud de la población gitana a nivel local.
4. Redefinir el rol de los agentes implicados en las políticas como capacitadores de gobernanza para la salud de la población gitana.

Capítulo 2

Resultados

En este capítulo presentaré los resultados de mi tesis doctoral a partir de los objetivos de investigación planteados y las publicaciones elaboradas para su consecución: un informe científico-técnico y tres artículos científicos.

"Implementation of the National Roma Integration Strategy and Other National Commitments in the Field of Health – Spain. A Multi-stakeholder Report on 2005-2014 Developments" (Garcia-Ramirez, Escobar-Ballesta & Lizana, 2015)

Este informe (Apéndice A), publicado por la IOM para la evaluación de la implementación de la ENIPG-S en España dentro del proyecto Equi-Health, responde al primer objetivo de esta tesis, es decir, desarrollar un marco de evaluación y redefinición de políticas de salud dirigidas a PG. Este trabajo representa, además, la base conceptual de la tesis y nutre al resto de publicaciones. Este informe se basa, en primer lugar y por primera vez en la literatura, en definir y entender las inequidades en salud de la PG y el fracaso de las políticas destinadas a eliminarlas como un problema retorcido (en inglés, *wicked problem*). Estos problemas tienen una naturaleza desestructurada, persistente e imprevisible que desbordan a las instituciones públicas a la hora de entender sus causas y darles solución (Australian Public Service Commission, 2007; Rittel & Webber, 1973). La literatura evidencia que el abordaje más efectivo para este tipo de

problemas es el que combina la perspectiva de múltiples agentes y las mejores evidencias disponibles (Australian Public Service Commission, 2007; Nelson, 2013; Rittel & Webber, 1973; Weber & Khademian, 2008).

Desde esta aproximación, desarrollamos un marco para evaluar la implementación de las políticas de salud dirigidas a PG así como transformar éstas. Este marco permite asumir la complejidad e incertidumbre de los problemas retorcidos y desarrollar cambios políticos transformadores que aseguren el enmarque del problema atendiendo al contexto y las diferentes perspectivas de los agentes, que permita el debate y la participación significativa, democrática y justa de todos los implicados, así como la reasignación equitativa de recursos, derechos y responsabilidades (Nelson, 2013; Petersen, Janssen, van der Sluijs, Risbey, Ravetz, et al., 2012; Weber & Khademian, 2008). Así, el marco para la evaluación y redefinición de políticas para garantizar la gobernanza de la salud en PG consta de cuatro fases recursivas e iterativas: (a) encuadrar el problema, (b) facilitar capacidad de colaboración para evaluar, (c) promover entendimiento compartido, y (d) planificar acciones y fortalecer el compromiso futuro.

A lo largo del informe se desarrollan cada una de las fases durante la evaluación de la implementación de la ENIPG-S en España, concretamente en Andalucía y Cataluña. Primero se enmarca el problema de la salud de la PG en España y se exponen las distintas respuestas políticas a nivel nacional y europeo que se han desarrollado para su abordaje (e.g., Década para la Inclusión de la PG, ENIPG-S). En segundo lugar, se presenta el proceso de colaboración establecido para la evaluación de la ENIPG-S en España a partir de la participación de múltiples agentes, una revisión de la literatura y la creación de una herramienta específica para evaluar la

implementación de políticas, el Roma Health Integration Policy Index (RHIPEX). A continuación, a partir del entendimiento compartido entre las distintas fuentes de información, se exponen los resultados de la evaluación de la ENIPG-S de acuerdo a las dimensiones del RHIPEX: titularidad, accesibilidad, sensibilidad y capacidad para conseguir y mantener cambios. Por último, con el fin de planificar acciones y fortalecer compromisos futuros se desarrollan prioridades que permiten redefinir las políticas de salud dirigidas a PG y se proporcionan estrategias y mecanismos para llevarlo a cabo.

"Taking Stock of Roma Health Policies in Spain: Lessons for health governance" (Escobar-Ballesta, Garcia-Ramirez & De Freitas, 2018)

Este trabajo (Apéndice B), publicado en la revista *Health Policy*, responde al segundo objetivo de la tesis: diseñar una herramienta para evaluar la gobernanza de la salud para la PG. Para ello, sintetiza la evaluación de la implementación de la ENIPG-S en España para su publicación y difusión como artículo científico, incorpora literatura actualizada e incluye la necesidad de abordar los desafíos de las políticas de salud dirigidas a PG a través del fortalecimiento de la gobernanza para su salud (Ottersen et al., 2014).

Este artículo enfatiza la importancia de establecer mecanismos de monitorización y evaluación de políticas prestando especial atención al diseño *ad-hoc* de la herramienta RHIPEX y su aplicación. El RHIPEX se inspira principalmente en el Migrant Integration Policy Index, que evalúa y compara las políticas destinadas a promover la integración de minorías étnicas y población migrante en distintos sectores (e.g., salud, educación, reagrupación familiar, empleo, discriminación, etc.) (MIPEX, 2015). También se nutre de los criterios propuestos por la WHO y

la IOM para evaluar las ENIPG-S y sus progresos (IOM, 2015; WHO, 2012) y de marcos dirigidos al estudio del acceso a los cuidados médicos (Aday & Andersen, 1974), al análisis de las políticas en salud para población migrante (Mladovsky, 2009) y a la mejora de la salud y el bienestar de la PG (Fésüs et al., 2012). En definitiva, el RHIPEX permite identificar fortalezas y limitaciones en la implementación de las políticas de salud dirigidas a PG en cuanto a titularidad, acceso, sensibilidad y capacidad para promover cambios, a través de un proceso recursivo e iterativo que integra información proveniente de los agentes involucrados y las evidencias disponibles.

A partir de los resultados obtenidos durante la implementación del RHIPEX para evaluar la ENIPG-S en España, el artículo concluye con una serie de lecciones aprendidas con el fin de redefinir las políticas y asegurar la gobernanza para la salud de la PG.

"Salud Sexual y Reproductiva en Mujeres Gitanas: El Programa de Planificación Familiar del Polígono Sur" (Escobar-Ballesta, Garcia-Ramirez, Albar & Paloma, 2018)

Este artículo (Apéndice C), publicado en la revista *Gaceta Sanitaria*, responde al cuarto objetivo de la tesis, es decir, identificar buenas prácticas profesionales que aseguren la gobernanza para la salud de la PG a nivel local. En él se pone de manifiesto los esfuerzos que realizan los profesionales para neutralizar el bajo impacto de las políticas de salud a nivel local. Éste es el caso de las profesionales del programa de planificación familiar del centro de salud (CS) Polígono Sur de Sevilla, que atiende a un 80% de PG que vive en condiciones de exclusión y presentan problemas de salud sexual y reproductiva (i.e., 17% de embarazos adolescentes, 35% de embarazos no planificados) (Maeztu, 2006). Siguiendo el mismo procedimiento para la

evaluación de la ENIPG-S, este artículo identifica los desafíos a los que se enfrentan las profesionales, los recursos que disponen y las estrategias que despliegan para asegurar servicios y una atención de calidad dirigida a mujeres gitanas.

Entre los desafíos, las profesionales destacan la falta de documentación entre las usuarias, la ausencia de información sanitaria sobre PG, la falta de un sistema de evaluación, la escasa interiorización de la prevención por parte de las usuarias y el bajo apoyo institucional. Para desarrollar su trabajo, las profesionales disponen de la Guía de Actuación en el Programa de Planificación Familiar en el Distrito Sanitario de Atención Primaria de Sevilla (Distrito Sanitario AP Sevilla, 2007). Sin embargo, ésta no incluye las recomendaciones de la ENIPG-S y no contempla actuaciones o adaptaciones específicas para las mujeres gitanas. Así, para afrontar los desafíos y ofrecer una atención ajustada las mujeres gitanas, las profesionales deben desarrollar estrategias informales no institucionalizadas. Entre ellas se destacan captaciones oportunistas, atención sin cita previa, adaptación de protocolos y prescripciones, seguimiento activo y personalizado, trabajo intersectorial, formación en competencial cultural, empatía y resolución de conflictos. Como resultado, las profesionales se sienten motivadas con su trabajo y con la respuesta de sus usuarias, lo que genera una mayor adherencia al programa, menor número de embarazos y una mayor sensibilidad por parte de las mujeres hacia la planificación familiar.

Este trabajo evidencia la necesidad de detectar, sistematizar y difundir buenas prácticas a nivel local y utilizar estas experiencias para nutrir las evidencias disponibles e informar las políticas con el fin de hacerlas más justas, sensibles y eficaces (EC, 2011). En este sentido, esta experiencia permite obtener recomendaciones para mejorar la eficacia e impacto de las políticas

y programas de salud sexual y reproductiva dirigidos a mujeres gitanas y asegurar la gobernanza para la salud a nivel local.

"El Reto de la Equidad en las Políticas Sanitarias Dirigidas al Pueblo Gitano en España" (Garcia-Ramirez, Escobar-Ballesta, Albar & Lizana, 2016)

Este artículo (Apéndice D) fue publicado como invitación al número especial sobre políticas públicas y abogacía social de la revista *Global Journal of Community Psychology Practice.* Este trabajo responde al tercer objetivo de la tesis, redefinir el rol de los agentes implicados en las políticas como capacitadores de gobernanza para la salud de la PG. Este trabajo resalta nuestro papel como psicólogos comunitarios durante la evaluación de la implementación de la ENIPG-S en España.

Partiendo de los principios y valores de la psicología comunitaria, nos apoyamos en el marco de los cambios políticos transformadores propuesto por Nelson (2013) para llevar a cabo dicha evaluación. Este marco sostiene que las políticas están determinadas por perspectivas plurales e intereses distintos de múltiples agentes y que están mediadas por relaciones de poder—generalmente desiguales—entre los implicados. Por ello, es necesario la movilización e implicación de todos los agentes para asegurar políticas de salud eficaces, justas y sensibles a partir de una definición compartida, de la identificación de soluciones y recursos necesarios, así como de su implementación y evaluación (Garcia-Ramirez, Balcazar & De Freitas, 2014; Nelson, 2013). Nuestra tarea como psicólogos comunitarios durante la evaluación de la implementación de la ENIPG-S en España ha sido desarrollar un proceso y herramienta de evaluación de políticas sostenidas en estas aproximaciones. Específicamente, nuestro rol ha sido,

el de capacitadores de la gobernanza para la salud de la PG. Esto ha supuesto facilitar dicho proceso, actuar como enlace entre los agentes e instituciones involucradas y establecer alianzas entre ellos, crear oportunidades para el compromiso activo de los agentes, asegurar la rendición de cuentas durante la evaluación, visibilizar y dar espacio a aquellas personas tradicionalmente excluidas del proceso, así como asesorar a los agentes involucrados (Bishop, Vicary, Browne, & Guard, 2009; Nelson, 2013).

En definitiva, ser capacitadores de gobernanza para la salud de la PG conlleva asumir los roles de mediadores, instigadores y abogados de la salud de esta población a lo largo de todo el proceso (Balcazar, Garate-Serafini & Keys, 2004). Estos roles pueden ser, por tanto, compartidos y asumidos por otros agentes involucrados en el diseño, implementación y evaluación de políticas de salud dirigidas a PG.

Capítulo 3

Discusión

Desde la perspectiva de los problemas retorcidos y los cambios políticos transformadores, esta tesis ha desarrollado un marco conceptual y metodológico para evaluar y redefinir políticas de salud dirigidas a PG así como una herramienta específica, el RHIPEX, para guiar dichos procesos. La evaluación de la implementación de la ENIPG-S en España—concretamente en Andalucía y Cataluña—ha puesto de manifiesto las limitaciones de las políticas actuales para garantizar la titularidad de la PG para beneficiarse del sistema público de salud, facilitar su acceso, ofrecer servicios ajustados a sus necesidades, y asegurar la sostenibilidad de los logros. Esta tesis también ha identificado fortalezas en las buenas prácticas de profesionales que están promoviendo la gobernanza en un contexto local a pesar de las limitaciones de las actuales políticas. Por último, también ha permitido redefinir y ampliar el rol de los agentes implicados como capacitadores de gobernanza para la salud de la PG en los procesos de diseño, implementación y evaluación de políticas.

Los resultados de la evaluación de la ENIPG-S en España son consistentes con los hallados por las evaluaciones de esta estrategia y de la Década para la Inclusión de la PG en otros países europeos (Brüggeman & Friedman, 2017; EC, 2016; Mirga-Kruszelnicka, 2017; Rorke, Matache & Friedman, 2015; Sándor, Kósa, Boruzs, Boros, Tokaji et al., 2017). El escaso impacto de estas políticas en la superación de las inequidades de la PG mantiene la brecha que separa su salud de la del resto de la población en toda Europa (Arora, Kühlbrandt, & McKee,

2016; Decade of Roma Inclusion, 2015; FRA, 2017; Jackson, Bedford, Cheater, Condon, Emslie, et al., 2017; La Parra, Gil-González, & Torre-Esteve, 2016; MSSSI, 2016; Sándor et al., 2017). La similitud de nuestros resultados con otros estudios y la persistencia de las inequidades en la PG europea nos permiten obtener algunas lecciones de nuestra experiencia para contribuir a conceptualizar políticas efectivas, sensibles y sostenibles dirigidas a combatir las inequidades en salud que sufre la PG. Las lecciones aprendidas que a continuación se presentan—introducidas escuetamente en algunas publicaciones de esta tesis—tratan de facilitar su diseminación y generalización en contextos similares.

La gobernanza para la salud de la PG necesita un abordaje interseccional e intersectorial, así como la inclusión de prioridades vinculadas a la salud en las otras políticas sectoriales. La evaluación de la ENIPG-S en España ha puesto de manifiesto la escasa sensibilidad y adaptación de las políticas para abordar los diversos determinantes personales y sociales de la salud. La PG se encuentra en una posición de mayor vulnerabilidad debido a la interacción de sus diversas identidades sociales (e.g., etnia, edad, género, estatus social y migratorio) con sus condiciones de vida (i.e., educación, empleo, vivienda, aceptación social, acceso a recursos). Esta falta de enfoque interseccional—que ha conducido a priorizar unos elementos sobre otros en políticas anteriores—ha perpetuado asimetrías y reproducido desigualdades en comparación con el resto de la población (Ferree, 2009; Hankivsky, Grace, Hunting, Giesbrecht, Fridkin, et al., 2014; Maya & Mirga, 2014; Oprea, 2003; Palencia, Malmusi & Borrell, 2014). Nuestro estudio ha permitido comprobar la validez de este enfoque en las prácticas de éxito llevadas a cabo en contextos locales significativos. Las profesionales del programa de planificación familiar del CS Polígono Sur ajustaron protocolos y prácticas para

atender las condiciones de vulnerabilidad de sus usuarias (i.e., mujeres, gitanas, pobres, en exclusión, con bajo nivel educativo y bajo acceso y adherencia a tratamientos y programas de prevención) consiguiendo mejorar no solo la accesibilidad sino también sensibilidad hacia la PG del programa. En este sentido, la literatura coincide que de poco sirve mejorar el acceso al SNS o capacitar a los profesionales en competencias culturales si simultáneamente no se adaptan los servicios a las personas a las que van dirigidos (Aiello, Flecha & Serradell, 2018).

La evaluación de la ENIPG-S también ha mostrado la necesidad de adoptar una perspectiva intersectorial en las políticas de salud, que obligue al sector sanitario a trabajar colaborativamente con el resto de ejes sectoriales que determinan la salud (e.g., educación, vivienda, empleo, etc.). Por ejemplo, para adaptar el programa de planificación familiar a las necesidades de las usuarias gitanas, las profesionales del CS Polígono Sur tuvieron que establecer lazos de colaboración con servicios sociales, las escuelas e institutos de la zona, e incluso con la propia comunidad gitana a través de las madres y suegras de las más jóvenes. Conseguir y mantener la salud de la PG no puede ser sólo un esfuerzo de las políticas sanitarias sino de todos los sectores involucrados en los problemas que presentan (La Parra & Jiménez, 2016). Nuestro estudio ha evidenciado las dificultades que supone llevar esto a cabo debido a la fragmentación de las políticas actuales y a la falta de comunicación y colaboración entre los distintos sectores y agentes. Asegurar la gobernanza para la salud de la PG desde estas aproximaciones pasa por la construcción de redes de políticas y alianzas multinivel que fomenten el diálogo, reduzcan los conflictos de intereses y promuevan acuerdos y estrategias transversales y sistémicas que protejan la salud de toda la PG (Dimova, Rohova, Hasardzhiev & Spranger, 2017; Fésüs et al., 2012; Kicksbusch & Gleicher, 2012; Mannheimer, Gulis, Lehto & Östlin,

2007; Rorke, Matache & Friedman, 2015). La evaluación de la ENIPG-S en España ha seguido esta aproximación a través de la construcción de una plataforma de agentes clave a distintos niveles, incluyendo representantes del asociacionismo gitano, organizaciones sociales pro-gitanas, mediación en salud gitana, investigación, planificación de políticas, coordinación de servicios sanitarios y servicios de políticas regionales, etc.

La gobernanza para la salud de la PG necesita de la participación transformadora de la PG. La evaluación de la ENIPG-S en España coincide con la literatura en que los esfuerzos por asegurar la participación de la PG en las políticas se han realizado a través de estrategias que la han instrumentalizado, siendo frecuentemente t*okenizada* y carente de representatividad y legitimidad (Maya & Mirga, 2014; Rorke, Matache & Friedman, 2015; Santos Carrillo, 2018; Tremlett & McGarry, 2013). Esto lo hemos podido comprobar al incluir en la plataforma de agentes únicamente a representantes de asociaciones gitanas y pro-gitanas y no a sus usuarios o a PG perteneciente a los contextos que evaluamos. Nuestro estudio ha puesto de manifiesto una creciente burocratización del asociacionismo gitano. Los recortes en la financiación de las asociaciones obligan a éstas a centrar sus esfuerzos en mantener nichos de trabajo y posiciones de influencia en lugar de detectar y adaptar sus programas a las necesidades y problemas de las comunidades en riesgo. Evitar esto pasa por fortalecer la gobernanza para la salud de la PG a partir de la participación real y efectiva a nivel local de grupos habitualmente silenciados (e.g., mujeres, menores, colectivo LGTBI+) con el fin de desafiar los discursos dominantes y los conflictos de intereses dentro del asociacionismo durante la formulación, implementación y evaluación de políticas (Boyce & Brown, 2017; De Freitas & Martin, 2015; Fésüs et al., 2012; FRA, 2017; Griffith et al., 2007; Hujo, 2016; Nelson, 2013; Tremlett & McGarry, 2013). Esta

participación dará lugar a escenarios comunitarios seguros y abiertos con capacidad para empoderar a la PG a ejercer influencia real en las políticas que les afectan, transformando éstas y sus contextos para hacerlos más justos, sensibles y eficaces (Balcazar, Suarez-Balcazar, Adames, Keys, García et al., 2012; De Freitas, García-Ramirez, Aambø, & Buttigieg, 2014; Paloma, Garcia-Ramirez, de la Mata, & Association AMAL-Andaluza, 2010).

La gobernanza para la salud de la PG necesita nuevos roles entre los agentes implicados. Durante la evaluación de la ENIPG-S en España hemos comprobado que el rol de los psicólogos comunitarios como capacitadores de la gobernanza para la salud de la PG puede extrapolarse a otros agentes implicados durante el proceso. Los actores encargados de implementar estas políticas suelen desarrollar nuevos roles como mediadores e instigadores para asegurar su eficacia en función de las demandas del contexto y la PG, las características de sus organizaciones y la ocurrencia de nuevas necesidades y desafíos (Balcazar, Garate-Serafini & Keys, 2004). Como ejemplo, las profesionales de planificación familiar del CS Polígono Sur aumentaron su conciencia crítica, las relaciones de colaboración positivas entre ellas y adquirieron competencias que les llevaron a redefinir los protocolos y prácticas, buscar y reasignar recursos, tomar decisiones y actuar para asegurar cuidados de salud sexual y reproductiva ajustados para las usuarias gitanas. La evaluación de la ENIPG-S también ha permitido identificar el trabajo de los mediadores en salud que facilitan el acceso de la PG a los servicios y mejoran la sensibilidad de estos (e.g., resolviendo asuntos administrativos, eliminando barreras culturales y de idioma, etc.). A pesar de que la figura del mediador está ampliamente reconocida en Europa, por sí solos, pueden crear el efecto perverso y paradójico de consolidar la brecha que separa a la PG del resto, creando dependencia de su figura o sin generar

cambios estructurales que combatan de raíz las inequidades (Belak, Dankulincova, Madarasova, van Dijk, & Reijneveld, 2017; La Parra & Jiménez, 2016; National Network of Health Mediators, 2017). Este desafío requiere ampliar el rol de capacitador de gobernanza para la salud de la PG más allá de la mediación con el fin de no solo puentear la brecha que separa a ésta del resto sino eliminarla definitivamente.

Nuestro trabajo ha puesto de manifiesto la importancia de capacitar a todos los agentes implicados para abogar por los derechos en salud de la PG. Según Aicher, Napier y Pickard (2010, p. 3), *abogar* es "el intento organizado por cambiar la política, prácticas y/o actitudes presentando evidencias y argumentos de cómo y por qué debe ocurrir el cambio." Abogar permite a los agentes instigar cambios e influir directamente en las instituciones y políticas, combatiendo los desequilibrios de poder y el antigitanismo (Balcazar, Garate-Serafini & Keys, 2004; Griffith et al., 2007). La capacitación de los profesionales sanitarios en abogacía para la salud ha sido señalada como un elemento central para la defensa de una salud pública y equitativa en España (González Rojo, Álvarez-Dardet, López Fernández, 2017). Igualmente, estos roles deben ser asumidos por la propia PG. Organismos como la CE y la WHO afirman que el progreso real en la salud de la PG llegará cuando ésta sea la abogada de su propia salud, diseñando, implementando y evaluando las políticas y programas que les atañen (Crowley, Genova, & Sansonetti; Skenderovska, 2011). Por ejemplo, el estudio sobre el programa de planificación familiar identificó la necesidad de capacitar a mujeres gitanas como abogadas de su salud sexual y reproductiva con el fin de concebir su salud y establecer sus expectativas de vidas a partir de sus fortalezas y no por imposiciones culturales o mandatos de género. La gobernanza para la salud de la PG necesita de la identificación, emplazamiento y capacitación de abogados

de salud gitana dentro de las comunidades, con poder y oportunidades para liderar cambios de manera colectiva que afecten a su salud (Abdkieeva & Covaci, 2018; Aicher, Napier, & Pickard, 2010; Reysen, Slobodnikova & Katzarska-Miller, 2016; Rorke, Matache & Friedman, 2015; WHO, 2013).

La gobernanza para la salud de la PG necesita mecanismos de rendición de cuentas que aseguren visibilidad, transparencia y corresponsabilidad. La evaluación de las políticas de salud ha seguido tradicionalmente el mismo planteamiento lineal que su diseño e implementación (i.e., describir el problema, establecer una agenda, recoger datos, plantear soluciones y seleccionar la mejor, formular la política y aplicarla). Su finalidad ha sido valorar en qué medida las acciones ejecutadas habían producido los efectos deseados, siendo sus resultados pocas veces usados para producir mejoras en éstas (Hegger, 2017; Sanderson, 2002). Para la evaluación de la ENIPG-S hemos optado por utilizar procesos y herramientas de evaluación ajustados a políticas que presentan desafíos durante su diseño e implementación (e.g., desequilibrios de poder, conflicto de intereses, escasez de evidencias, etc.) (Head & Alford, 2015; Nirenberg, Brawerman & Ruiz, 2000; Sanderson, 2002). Esta evaluación ha permitido identificar debilidades y fortalezas desde las que re-conceptualizar las políticas según las exigencias de la población y el contexto en el que se aplican, asegurando la gobernanza para la salud de la PG en comunidades más justas y saludables (Kicksbusch & Gleicher, 2012; Nelson, 2013; Nirenberg, Brawerman & Ruiz, 2000; Sanderson, 2002). La estrategia Salud 2020 afirma que “las políticas deberían ser implementadas como experimentos a gran escala en el que los esfuerzos por monitorizarlas y evaluarlas supongan un mecanismo esencial para que la comunidad aprenda de las experiencias adquiridas en la práctica y se adapte en consecuencia”

(WHO, 2013, p. 58). La identificación, sistematización, diseminación e institucionalización de buenas prácticas y experiencias de éxito a nivel local puede arrojar luz sobre estos desafíos, no solo retroalimentando las políticas sino también aportando información a áreas tradicionalmente libre de evidencias (EC, 2010; Fésüs et al., 2012). Mientras se debate en profundidad la recogida de datos desagregados por etnia, nuestro trabajo ha planteado la necesidad de fortalecer y diversificar—en lugar de acumular—la base de evidencias en salud de la PG a partir de los conocimientos y experiencias del asociacionismo gitano y los proveedores de servicios que implementan día a día las políticas.

La evaluación de la ENIPG-S en España también ha constatado cómo la descentralización de poderes y competencias y la escasa diseminación y evaluación dificultan su impacto. La ENIPG-S ha sido incapaz de contravenir la pérdida de derechos en salud como resultado del Real Decreto Ley 16/2012—impuesto por el gobierno central el mismo año en que adopta la estrategia europea—a pesar de contar con el apoyo de las instrucciones de los gobiernos regionales de Andalucía y Cataluña que pretendían asegurar este derecho (Boletín Oficial del Estado, 2012; Junta de Andalucía, 2012; Servei Catalá de Salut, 2012; Servicio Andaluz de Salud, 2012). Por otro lado, la ENIPG-S y el resto de compromisos asumidos por España son desconocidos por la comunidad gitana, por la sociedad civil y por muchos responsables encargados de implementarlas y gestionarlas. Además, las evaluaciones y monitorizaciones de la Década y la ENIPG-S en España han tenido lugar principalmente a nivel nacional, con indicadores *superficiales* relativos a la justificación de gastos o al tipo de acciones implementadas, y realizadas por los mismos encargados de diseñarlas (MSSSI, 2013, 2015, 2016, 2017). Todo ello ha puesto de manifiesto la necesidad de desarrollar e implementar mecanismos de

monitorización durante todo el proceso de gobernanza (e.g., selección agentes involucrados, diseño, implementación, etc.) y evaluación de resultados que permitan ajustar las políticas nacionales a las necesidades locales, especialmente en contextos comunitarios con mayor riesgo de vulnerabilidad (Hujo, 2016; Kickbusch & Gleicher, 2012; Ottersen et al., 2014). La literatura recomienda realizar la monitorización y evaluación de políticas desde coaliciones compuestas por miembros de la sociedad civil, organizaciones sociales, instituciones públicas y gubernamentales y otros agentes claves de la comunidad en particular (Fox, 2016; Fox & Aceron, 2016; Mannheimer, Gulis, Lehto, & Östlin, 2007; Mittlemark, 2007). Para ello es necesario que los agentes integren la importancia de evaluar, desarrollen capacidades y habilidades para ello y lo asuman como parte de su rutina; y que sus organizaciones proporcionen los recursos necesarios y utilicen los resultados para revertirlos en la mejora de sus políticas. La evaluación de la ENIPG-S en España ha constatado la necesidad de incorporar, además, la figura de los abogados de salud gitana. La evaluación hecha desde *lobbies* políticos está encaminada principalmente a parchear fallos durante la implementación. Evaluar desde coaliciones locales de múltiples agentes que incluyen abogados de salud gitana permite cuestionar las políticas generando evidencias de su funcionamiento e impacto real, identificando y modificando las causas de su fracaso, y reconociendo aliados y adversarios que pueden contribuir o entorpecer su eficacia (Fox, 2016; Fox & Aceron, 2016). La evaluación desde una perspectiva de abogacía se enfoca al cambio, con intención de crear sinergias e influenciar directamente en las políticas y en las comunidades. Esto permite movilizar y comprometer a todos los implicados en garantizar la transparencia, corresponsabilidad y rendición de cuentas, evitando la descentralización y el desequilibrio del poder, la exención de obligaciones ante los

fracasos o el cruce de culpas y acusaciones (Fox, 2016; Fox & Aceron, 2016; Griffith et al., 2007; Hujo, 2016; Mannheimer et al., 2007; Mittlemark, 2007; Nirenberg, Brawerman & Ruiz 2000).

Limitaciones y Consideraciones para Investigaciones Futuras

Nuestro estudio tiene limitaciones que deberían ser tenidas en cuenta para ponderar el alcance de nuestras afirmaciones y dirigir investigaciones futuras. En primer lugar, la evaluación de la implementación de la ENIPG-S en España únicamente tuvo lugar en Andalucía y Cataluña y refería, principalmente, a PG nacional. Esto implica, por un lado, que este estudio ha servido para evaluar de manera general las razones de éxito y fracaso de la implementación de esta política. Sin embargo, no ha evaluado de manera sistemática y sostenida un caso en particular en un contexto más específico. Por otro lado, los resultados de este estudio no pueden ser generalizados a las demás CCAA, al resto de actores involucrados en la salud de la PG, ni a toda la PG en su totalidad. Específicamente, la información obtenida a través de las entrevistas a los agentes de la plataforma refleja únicamente su realidad, ayudándonos—junto con las evidencias—a crear una fotografía general de la compleja implementación de la ENIPG-S en dos contextos. A pesar de esto, el proceso, la herramienta y lecciones aprendidas de este trabajo pueden ser útiles para ser aplicados en contextos y poblaciones con características similares a las que se han utilizado en este estudio.

La extensión de la plataforma de agentes, con representación de diferentes niveles de poder, y repartida en dos CCAA, complicó participar activamente en el proceso así como mantener las sinergias creadas durante los foros comunitarios. Igualmente, la fragmentación del

sector de la salud y de la propia ENIPG en diferentes áreas (i.e., salud, empleo, educación y vivienda) impidió obtener una perspectiva más ajustada de su implementación y sus relaciones con otras áreas. Además, confiar en la representación de la PG únicamente a través de la participación de las asociaciones nos limitó obtener una perspectiva más real y directa sobre sectores no representados por ésta, como la PG extranjera o aquella que vive segregada en asentamientos. De manera similar, en nuestro estudio hemos tenido la oportunidad de profundizar, a través de un estudio cualitativo, en la implementación de la ENIPG-S en un área de salud determinada. Elegimos salud sexual y reproductiva en mujeres gitanas por ser un desafío que despierta gran interés tanto en la intervención como en la investigación. No obstante, podríamos haber elegido otros problemas de salud tradicionalmente más olvidados en esta población y que son esenciales de abordar (e.g., salud visual y auditiva).

Inicialmente, esta tesis surgió con la tarea encargada por la IOM para evaluar la implementación de la ENIPG-S en España para el proyecto Equi-Health. Sin embargo, la estrategia no fue realmente implementada hasta la publicación de su Plan Operativo—posterior a la recogida principal de datos de este estudio. Esto, unido a la escasa literatura sobre la implementación y evaluación de políticas de salud dirigidas a PG en España, ha limitado la aproximación a la evaluación de la ENIPG-S desde las evidencias. Como consecuencia, en nuestro estudio se ha dado más peso a las narrativas de los agentes y a su experiencia durante la implementación de dicha política y otros compromisos nacionales para la superación de las inequidades en salud de la PG. De manera opuesta, a la hora de enmarcar el problema de la salud de la PG en España, nos hemos decantado principalmente por informes y artículo científicos publicados. Indagar sobre este tema durante las entrevistas con los agentes de la plataforma nos

hubiera permitido obtener un mejor encuadre del problema, incluyendo necesidades y problemas de salud detectados por estos en su experiencia con PG que la literatura científica no tiene en cuenta. No obstante, las discrepancias entre las prioridades en salud marcadas por la ENIPG-S y las identificadas por los agentes quedaron recogidas durante la evaluación de la sensibilidad de las políticas.

Por último, el RHIPEX no incluye un indicador para evaluar, en sí mismo, la existencia de mecanismos de evaluación de políticas en la dimensión "Capacidad para conseguir y mantener cambios." Dadas las respuestas negativas a esta esta cuestión durante las entrevistas—y dado que la única evaluación de políticas de salud gitana disponible en la literatura era la del plan anterior—decidimos erróneamente eliminar este indicador ya que la ausencia de evaluación es igual de significativa que su presencia. Por esta razón, se incorporó dicho indicador al instrumento en proyectos posteriores (Garcia-Ramirez, 2016). Por último, con el fin de evitar la fragmentación de las políticas y aumentar la aproximación intersectorial e interseccional en todas las políticas dirigidas a PG, sería útil e interesante ampliar el RHIPEX incluyendo otras áreas relevantes para mejorar la inclusión de la PG más allá de la salud (e.g., discriminación, educación, vivienda, perspectiva de género, empleo, etc.). Esto nos permitiría disponer de un nuevo índice más general, el Roma Integration Policy Index, a semejanza de su instrumento homólogo para población migrante (MIPEX, 2015),

Conclusion

Roma health policies in Europe and Spain have evolved throughout history; from the first, which sought their punishment and assimilation, to the current ones, which seek to integrate

and include them in society (Ringold, Orenstein & Wilkens, 2005). Although the latter have placed the Roma in the political map and stoked the debate on their appalling state of health, these were not enough to fill in the health gap that separates the Roma from the rest of the population. The ameliorative and palliative nature of these policies—formulated from within a normative and mainstream system and without questioning oppressive structures—have maintained the status quo of the Roma and the inequities that condemn them to an inhuman situation (MSSSI, 2016; Rorke et al., 2015; Sándor et al., 2017; Vincze, 2014).

The United Nations' 2030 Agenda for Sustainable Development trusts to 'transform the world' by attacking the root causes that generate and reproduce inequities and not just their symptoms (Hujo, 2016). From this perspective, our study has highlighted the need to strengthen governance for Roma health through transformative policies committed to the values of social justice, equity and human rights. Hence, there is a need for new ways of policy-making that emphasize the establishment of synergies, the questioning of power structures and pre-established systems, as well as the co-production of knowledge between the values and experiences of all stakeholders and the best available evidence (Griffith et al., 2007; Nelson, 2013; Ottersen et al., 2014; Prilleltensky, 2014). This study has evidenced that strengthening governance for Roma health lies in the role of Roma health advocators—within communities and institutions—to unleash virtuous circles during the conceptualization of policies from an intersectional, intersectoral and health-in-all policies approach, as well as during their evaluation through multi-level accountability mechanisms that ensure visibility, transparency and co-responsibility among all those involved.

During the realization of this study, our determination has always been to conduct a critical and policy-relevant research to address the wicked challenge of ensuring the implementation of Roma health policies. We hope the results and lessons learned from this doctoral thesis allow assessing and redefining fair, effective and equitable health policies that accompany and facilitate the Roma to move from a situation of suffering to one of health, wellbeing, and thriving.

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Apéndice A

Garcia-Ramirez, M., Escobar-Ballesta, M., & Lizana, T. (2015). Implementation of the NRIS and Other National Commitments in the Field of Health – Spain. A Multi-stakeholder Report on 2005-2014 Developments. International Organization for Migration.

Implementation of the National Roma Integration Strategy and Other National Commitments in the Field of Health

SPAIN

A multi-stakeholder perspective report on 2005 - 2014 developments

This Progress Report from a multi-stakeholder perspective on the implementation of the NRIS (National Roma Integration Strategy) and other national commitments in respect to Roma Health was undertaken by IOM within the framework of the project "Fostering Health Provision for Migrants, the Roma, and Other Vulnerable Groups" (Equi-Health). The EQUI HEALTH project is co-financed under the 2012 work plan, within the second programme of Community action in the field of health (2008 – 2013), by direct grant awarded to IOM from the European Commission's DG for Health and Consumers (SANTE), through the Consumers, Health, Agriculture and Food Executive Agency (CHAFEA).

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CONTENTS

ACRONYMS

ASPCAT	Public Health Agency of Catalonia *(Agència de Salut Pública de Cataluña)*
CatSalut	Catalan Healthcare Service *(Servei Catalá de la Salut)*
AACC	Autonomous Communities (*Comunidades Autónomas)*
CBO	Community-based organization
CESPYD	Coalition for the Study of Power, Health and Diversity
CSO	Civil Society Organizations
DG	Directorate General
DG SANCO	European Commission's Directorate General for Health and Consumers
DRI	Decade of Roma Inclusion
EC	European Commission
EU	European Union
IOM	International Organization for Migration
MIPEX	Migrant Integration Policy Index
NGO	Non-Governmental Organizations
NHS	National Health System (*Sistema Nacional de Salud)*
NRIS	National Roma Integration Strategy
PHC	Primary Healthcare
RDL	Royal Decree-Law (*Real Decreto Ley)*
RIPEX	Roma Integration Policy Index
SAS	Andalusian Healthcare Service *(Servicio Andaluz de Salud)*
ToR	Terms of Reference of the Equi-Health project
TRHP	Transformative Roma Health Policies
VIP	Voluntary Interruption of Pregnancy
WHO	World Health Organization

EXECUTIVE SUMMARY

Introduction Building collaborative capacity among stakeholders in order to develop transformative Roma health policies

In February 2013, the Migration Health Division of the Regional Office for Europe and Central Asia of the International Organization for Migration (IOM) launched the project "Equi-Health: Fostering Health Provision for Migrants, the Roma and Other Vulnerable Groups." Equi-Health´s sub-action "Roma Health" seeks to improve the accessibility, adequacy, adaptability, satisfaction with and the quality of health assistance, preventive care, and health promotion services for Spanish and foreign (EU and third country nationals) Roma. The first stage of this project focuses on elaborating progress reports from a multi-stakeholder perspective on the implementation of the National Roma Integration Strategy (NRIS) and other national commitments with respect to Roma Health.

The Roma are one of the largest minorities in Europe and the main ethnic group in Spain. Roma health is a challenge that is extremely difficult for European society to tackle. The isolation, discrimination, and poverty in which many of them live are unacceptable sources of inequity that have been in place for hundreds of years.

In order to tackle this problem, in 2005, the European governments committed to a Decade of Roma Inclusion (DRI; 2005-2015) to "combat discrimination, poverty, and exclusion against the Roma population, and to reduce the unacceptable gaps between this population and the rest of society in education, housing, employment, and health." A few years later, the World Health Organization's (WHO) programme, Health 2020, provided a new framework for understanding public health in Europe as a response to the gaps in health caused by the economic crisis. However, in 2010 the European Commission (EC) elaborated a report on the Economic and Social Integration of the Roma in Europe (European Commission, 2010a), which evidenced the relative failures of these efforts, such as the existing gap between planning and implementation, the weak inclusion of strategies at different levels, the low participation of the Roma community, the inadequate use of funds, etc.

These assertions imply the acknowledgement that the Roma people's health inequities are a 'wicked problem,' that is, a problem that is extremely difficult to broach and solve (Rittel & Webber, 1979). Indeed, the chronic failure of existing policies intended to put an end to the Roma inequities may be explained by the fact that (a) Roma health has never been considered or defined as a social problem; (b) the political concern around Roma health has not translated into effective policies; and (c) the complexity of the problem does not derive from scientific but political and social difficulties which would require building collaborative capacity among all stakeholders to solve it.

We need to find innovative strategies to actively engage all the stakeholders in the design, implementation and assessment of Transformative Roma Health Policies (TRHP). Collaboration among the different stakeholders must be part of a permanent and proactive process of transformation to constantly shape the problem, as well as the strategies and actions implemented to solve it. Furthermore, stakeholder involvement needs to be implemented as a process of community mobilisation for building collaborative capacity among all stakeholders, leading to the development of shared understanding, and collective commitment and action for the future (De Freitas et al., 2014).

This report is the result of the work done by Spanish consultants to tackle the challenge of ensuring the equity of health policies for the Roma population, adopting the viewpoint of the different stakeholders involved while developing their capacity for collaboration and producing shared understanding of the problem (Petersen et al., 2012). This report is organized in the following chapters: (1) Framing the problem, (2) Building and releasing collaborative capacity to transform, (3) Promoting shared understanding from evidences and stakeholders and (4) Planning the future.

Framing the problem

According to official data, the population of Spain is currently 47,129,783 people. Out of the total population, between 700,000 and 970,000 people (1.5% - 2.1%) are Roma, making Spanish Roma the biggest ethnic minority in the country (Fundación FOESSA, 2008). The Roma population is diverse and heterogeneous, and there are clear differences between national and foreign Roma. Nevertheless, there are also commonalities between them - for example, location, demography, and family structure.

The health of national Roma has improved in recent years thanks to housing improvement, the implementation of universal healthcare, the rehabilitation of marginal areas, and the expansion of compulsory schooling (Fundación Secretariado Gitano, 2012; Laparra et al., 2012). In spite of all this, work still needs to be done in order to reduce the social determinants and health inequities between the general population and the Roma minority, and between national and foreign Roma. The national Roma population has a more negative view of health, worse eye and ear health, and more traffic and domestic accidents than the rest of the non-Roma population. Some Roma children are not vaccinated, do not get regular paediatric check-ups, and have a deficient or unbalanced diet. Adults do not utilise preventive services and are more prone to suffer from cardiovascular, bone, joint, and chronic diseases. In particular, women tend to suffer from obesity, they make fewer periodical visits to the gynaecologist and suffer more mental health problems than that of the rest of the Spanish population (La Parra, 2009; Laparra, 2007, 2011; Ministerio de Sanidad y Consumo & Fundación Secretariado Gitano, 2007).

Although there is no reliable information about the health of foreign Roma living in Spain, several inferences can be made on the basis of data obtained in their countries of origin (Hajioff & McKee, 2000; McKee, Balabanova & Steriu, 2007; Parekh & Rose, 2011). Their life expectancy is 10 to 15 years lower than the rest of the population in their countries, with higher mortality rates among young adults and children. Many of them suffer from malnutrition and infectious diseases, as well as alcohol and drug abuse. The number of people with psychiatric or mental disorders is six times greater than in the rest of the population, and there are higher rates of teenage pregnancies, which increase child vulnerability. There has been an increase in the mobility of citizens from Eastern Europe since Bulgaria and Romania formalised their membership in the European Union (EU) in 2007, together with a waiver visa policy for Western Balkans' citizens (McKee, Balabanova & Steriu, 2007). This, together with the rise of xenophobic policies in EU member states such as Italy or France[3], has made of Spain a preferred destination for many of the Roma population from Eastern European countries. Their arrival has become a challenge to human rights, and a possible risk for

[3] El ministro del Interior francés arremete contra los gitanos, *El País,* September 2013
http://internacional.elpais.com/internacional/2013/09/24/actualidad/1380022331_876484.html
[3] Miles de gitanos protestan en Roma contra la xenofobia, *El País,* June 2008
http://internacional.elpais.com/internacional/2008/06/08/actualidad/1212876007_850215.html

public health, since they get here in very precarious conditions and with no chances of finding a job: they do not have or look for housing and many of them live in temporary and unsanitary settlements where the same subhuman conditions of their countries of origin are replicated. Persecuted and stigmatised for their vulnerability, their precarious health condition contributes further to their marginalisation, creating new risks and suffering.

To put an end to these inequalities, in April 2011 the European Commission adopted the EU Framework for NRIS up to 2020 (European Commission, 2011), by which EU countries committed to revising existing strategies and to developing new ones in order to improve Roma inclusion in European societies with respect to education, employment, housing and health. By 2012, each EU member state had elaborated a National Strategy (European Commission, 2012) intended, on the one hand, to complement and reinforce the EU's equality legislation and to support policies and authorities at the national, regional, and local levels in monitoring, sharing, and strengthening effective and comprehensive approaches to Roma health; and, on the other, to build a coherent network to promote dialogue and participation among all key stakeholders and to delineate strategies and interventions to support capacity building and cooperation in order to address the specific needs of Roma.

In Spain, the NRIS was developed by the Ministry of Health, Social Services, and Equality (Ministerio de Sanidad, Política Social e Igualdad, 2012b) and implemented through the Operational Plan (*Plan Operacional;* 2014-2016) (Ministerio de Sanidad, Política Social e Igualdad, 2013a). Concerning adults' health, the targets are to improve the perception of the health status of the Roma population and to reduce traffic accidents and smoking. Special attention is also given to reducing obesity among women and to reducing the number of women who have never gone to thegynaecologist. In relation to child population, the NRIS aims to reduce the number of children suffering domestic accidents and increase oral healthcare. The key areas of NRIS implementation are: (a) promoting policies and actions aimed at reducing health inequalities, (b) reorienting health services towards equity, (c) fostering health promotion throughout the life course, (d) establishing mechanisms to ensure positive impact on Roma health, (e) promoting Roma participation, (f) promoting intersectoriality and (g) supporting and promoting diversity training.

Building and releasing collaborative capacity to transform

Transformative policy change requires that new policies are both evidence and a discursive, building policies based on the values and participation of all stakeholders (De Freitas et al, 2014; Nelson, 2013). Regarding the evidence-based approach, the expert team conducted desk research including literature review, legal review and policy research. The researchers further collected data and combined information from various sources in order to obtain the most comprehensive overview of the foreign and national Roma population of Spain, and more specifically in the Autonomous Communities (AACC) of Andalusia and Catalonia. To carry out the discursive approach, a coalition or stakeholders network was constituted in order to build collaborative capacity among them. The coalition comprised representatives of organizations with relevant role in the field of Roma health. Assuming a systemic view, policymakers, managers, healthcare providers and users' representatives were invited to join the coalition.

A new tool, **the RIPEX** (Roma Integration Policy Index) was developed in order to analyse and integrate the results of the stakeholder interviews and the information obtained in the desk review. This index was promoted by the network set up in Equi-Health to assess and contrast how sensitive

health policies are towards the Roma population. The indicators were selected from the WHO's assessment recommendations for the health element of the NRIS, the MIPEX (Migrant Integration Policy Index) and those required by the IOM in the Equi-Health´s Terms of Reference.

The resulting RIPEX categories and indicators used in this report are: (a) *Entitlement to Healthcare* (Requirements for obtaining entitlement, Co-payments, and Coverage); (b) *Access to Healthcare Services* (Accessibility barriers, Consequences, Policies and strategies to suppress accessibility barriers, and Roma health mediation); (c) *Responsiveness of Healthcare Services* (Health inequalities defined in the NRIS, Policies to make healthcare services more sensitive, and Adaptation strategies of healthcare services and providers); (d) *Achieving and Sustaining Change* (The political and economic context of the NRIS, Associationism, collaboration and participation of the national and foreign Roma community, Collaborative work among multiple, and Promoting inter-sectoral action).

Promoting shared understanding to transform Roma health policy

Regarding **entitlement to healthcare**, the NRIS in Spain and its Operational Plan are based on the universalisation of the National Healthcare System (NHS). However, recent cutbacks and changes in the Spanish healthcare legislation have led to the dismantling of the system and some of its core elements. All these have affected both the national and foreign population—Roma and non-Roma—as well as the implementation of the NRIS. This new healthcare model has worsened the low socio-economic conditions of most vulnerable people, especially the foreign Roma. Moreover, paperwork to obtain a Health Card involves bureaucratic procedures and additional documentation that are further barriers for the Roma population. As a response, some AACC such as Catalonia and Andalusia, have developed strategies to ensure healthcare access for those excluded from the system by the law. Nevertheless, many challenges are still threatening the entitlement of the Roma to healthcare.

The NRIS establishes the **accessibility to the healthcare system** as one of the strategic lines of action to improve Roma health. National and foreign Roma have developed non-normative patterns of access to and use of healthcare services due to their historical marginalization and persecution; the bad public transport connection between their neighbourhoods and settlements with healthcare services; and the blindness of the healthcare system about the Roma culture, among others. To overcome these challenges, national and regional governments have developed policies to ensure healthcare access. Healthcare centres have also developed strategies to facilitate access (e.g., specific health programs and committees, information points). However, the most effective actions have been conducted by healthcare providers and social workers from civil society organizations (e.g., by taking part in community interventions and commissions with several other agents in the area, accompany programs, developing alternative ways to access, etc.). In this undertaking, the health mediation processes play a central role in enhancing Roma's accessibility to medical services, while also improving the health of this community and bringing the NHS and communities closer.

The NRIS and its Operational Plan cover **responsiveness of healthcare services** as a relevant subject through objectives aimed at reducing specific Roma health inequities and strategic lines of actions. However, attention has been drawn to some NRIS limitations - its focus on the national Roma population, its exclusively biomedical perspective, and the fact that its objectives are neither interconnect nor integrated with other policies and strategies of the NHS. Nevertheless, some efforts have been made to make the systems and its services more responsive towards the Roma

community. At policy level, there are regional and national plans to culturally train providers. Also, reports and guides about Romma health have been published and some healthcare campaigns have been culturally adapted. This is complemented by the adaptation of general protocols by some healthcare providers working in centres with high rates of Roma users. Other revisions are related to communication, balancing assistance with their religious beliefs, economic situation, etc. There are also other adaptations that demand great effort from providers, subsequently causing burnout. Such adaptations include adopting a more proactive attitude and having constantly monitor and locate Roma users.

To **achieve and sustain change**, the NRIS and the Operational Plan intend to enhance Roma health through administrative cooperation and stakeholders' participation. To achieve this, certain challenges should be taken into account. For example, the NRIS is being ineffectively implemented due to the current economic and political context in Spain. Moreover, the strategy is not sufficiently publicised and its implementation entails conflicts of interests among different institutions and bodies at different levels. The Roma are little engaged in policy planning and implementation, and there exists institutional discrimination among them. On the other hand, national Roma and their associations do not sympathise with, and even discriminate against, foreign Roma, who also lack forms of associationism. Besides, there is lack of international cooperation and networking among stakeholders. All this entails a progressive bureaucratization of Roma associations, which can hinder the construction of a solid system to encourage all Roma sectors to take active part in the process of improving their health status.

Planning the future

In order to achieve quality Transformative Roma Health Policies (TRHP) development and implementation, we must take into account that these are the outcomes of an innovation process that put into practice both evidence-based and discursive approaches. Hence, building TRHP from a multi-stakeholder perspective would be one thing, and implementing them would be another (Frank & Atkins, 1981; Meyers et al., 2012). When planning the future, some challenges may arise, such as the lack of common and shared interests and goals, unrealistic expectations, the lack of evaluation, communication and organizational barriers, segmentation of the network, unbalanced power relations, resistance to change and maintaining the status quo, lack of resources, etc. (Suarez-Balcazar et al., 2007). Bearing this in mind, TRHP from a multi-stakeholder perspective should follow principles to guide the development and implementation of Roma health priorities through specific community tools.

The principles of TRHP would be: (1) to seek **the effective involvement of multiple stakeholders in participatory mechanisms by building collaborative capacity;** (2) to be based on **health in all policies** and **intersectoral actions for health**; (3) to **better monitor and report progress, and** to **develop evaluation capacity among stakeholders**; (4) to **redefine the role of policy promoters;** (5) to **advocate for the elimination of institutional discrimination;** (6) to **assure cultural competence among stakeholders;** (7) to **institutionalize health mediation;** and (8) to **promote Roma health literacy.**

The TRHP priorities identified during stakeholder interviews and coalitions entail: (a) **strengthening entitlement to healthcare** (e.g., protecting national and European health rights, reviewing administrative procedures to obtain the Health Card, etc.); (b) **assuring accessibility to the healthcare system** (e.g., denouncing human rights, distinguishing access and accreditation with

care, reviewing formulas to access, increasing health mediation processes, etc.); (c) **promoting responsiveness in healthcare services** (e.g., including foreign Roma in the NRIS, developing a culture of care and a vision of community health, health in all policies, increasing diverse staff and health mediators, disseminating good practices, etc.); and (d) **achieving and sustaining change** (e.g., strengthening the Roma associative movement by promoting collaborative work, giving Roma a central role, employing community resources and methodologies, fostering criticism among Roma associationism, improving the viability of the NRIS—a higher budget would contribute to further the dissemination, commitment and sustainability of the strategy).

TRHP development and implementation follow an ecological approach, relying on continuous innovation by which stakeholders "learn by doing", and making ample use of emerging technologies such as online platforms. The use of these platforms, such as the creation of a Roma Tool Box, would allow to work in an exchange network that allows connecting multiple stakeholders at local and global levels who are engaged in transforming and building healthier Roma communities. Moreover, it would be an excellent support infrastructure that would provide opportunities for building capacity systems for change, ensuring the success of intervention and evaluating those within an open system environment.

1. INTRODUCTION BUILDING COLLABORATIVE CAPACITY AMONG STAKEHOLDERS TO DEVELOP TRANSFORMATIVE ROMA HEALTH POLICIES

In February 2013, the Migration Health Division of the Regional Office for Europe and Central Asia of the International Organization for Migration (IOM) launched the project "Equi-Health: Fostering Health Provision for Migrants, the Roma, and Other Vulnerable Groups." Equi-Health´s sub-action "Roma Health" seeks to improve the accessibility, adequacy, adaptability, satisfaction with and quality of health assistance, preventive care, and health promotion services for national and foreign Roma—EU and third country nationals. The first stage of this project focuses on elaborating progress reports from a multi-stakeholder perspective on the implementation of the National Roma Integration Strategy (NRIS) and other national commitments with respect to Roma Health.

This report describes the activities of the Coalition for the Study of Health, Power, and Diversity (CESPYD[4]), the Centre of Community Research and Action at the University of Sevilla, and the Public Health Agency of Catalonia (ASPCAT) as national consultants for the elaboration of the progress report on the NRIS in Spain. In this introductory chapter, we describe the background on the health challenges faced by the national and foreign Roma community in Spain. Then, the reasons for the failure of previous policies are analysed, followed by a rationale for the adoption of a perspective to build collaborative capacity among the different stakeholders to face these challenges.

1.1. Background

Roma health remains a difficult challenge for European society. The conditions of isolation, discrimination, and poverty in which many Roma people live represent an unacceptable source of inequity in Europe. This situation represents the secular oppression that Roma have suffered ever since arriving in Europe from the Punjab region in India in the Middle Ages, when they were mistenly called *gypsies* as it was thought they come from Egypt. In Europe, which was then controlled by the Catholic Church, the Roma were soon persecuted for heresy, as they engaged in practices such as divination and chiromancy. As a matter of fact, it was the prestige that they soon gained as artists, musicians, storytellers, and magicians that made the Catholic Church fear losing its control over an ignorant and superstitious society (Strochlic, 2011). In 1554, being Roma was punished with death penalty in England if they had not left the country and, hundred years later, 15 European countries enforced laws intended to secure the deportation of Roma people and the annihilation of their communities. These laws forced them to adopt a travelling way of life (Strochlic, 2011).

In Spain, the history of Roma oscillates paradoxically between repudiation and fascination as well. Repudiation comes from them being seen as thieves and liars; fascination arises from the sensitivity and profoundness of their music, their dance, and their artistic talent – for example in bullfighting. This paradox is reflected in the norms and laws enforced in Spain since Roma entered the peninsula through the Pyrenees and coming from Africa through the Strait of Gibraltar. At first, the Roma were welcome and protected. Later, they were expelled and forbidden to speak their language and to maintain distinguishing traits. After Franco's death, racial discrimination became a criminal offense, and the regulations of the Guardia Civil regarding the surveillance of and control over Roma customs and ways of life were revoked (FAKALI, 2013).

[4] www.cespyd.es

Between 12 and 15 million Roma currently live in Europe, of which around 10 million live in the EU. These figures indicate that in some countries the Roma population is an important part of the total. For example, the Roma represent 10% of the total population of Bulgaria, 9% of the population of Slovakia, and 8% of the population of Romania. Furthermore, the Roma population is the poorest ethnic minority in Europe. They are ten times poorer than the rest of the population and their life expectancy is about 15 years lower than that of the average European citizen (Parekh & Rose, 2011). In Spain, it is estimated that 77% of the Roma population live in relative poverty–with 37.5% living in extreme poverty, compared to 37.2% in Bulgaria—where 80.1% live on less than USD 4.30 a day, and 43.1% in Romania—where 68.8% live on less than USD 4.30 a day (Fundación Secretariado Gitano, 2012).

In spite of the fact that Roma have lived in Europe for nearly a thousand years, they are still seen as foreigners and prejudice against them is deeply rooted in the whole continent. Segregation prevails in many countries and Roma people are constantly forced to move and to settle in the peripheries of urban centres or in segregated areas with no social services and where they suffer constant discrimination, poverty, and police brutality. Authorities tend to see delinquency and unemployment in Roma communities as irremediable ethnic problems and these are then used to perpetuate and justify the cycle of segregation and persecution (Strochlic, 2011).

1.2. Failure of European responses

The determination to expand the EU offered the opportunity for the European Commission (EC)–together with the Open Society Foundation and the World Bank—to organise the conference "Roma in an Expanding Europe: Challenges for the Future" in 2003 to raise awareness of the need to implement policies that enable the integration of Roma in European societies. Roma leaders, government representatives from Central and Eastern Europe as well as other international leaders were invited to this conference, where emphasis was placed on five fields of action: discrimination, education, employment, housing, and health. Moreover, fighting poverty and adopting a gender perspective became transversal concerns. In this way, participating countries committed to inaugurating a new decade, starting in 2005, to promote policies of inter-sectoral integration.

Consequently, the Decade of Roma Inclusion[5] (DRI; 2005-2015) emerged as the first political commitment among some European governments[6] to "combat discrimination, poverty and exclusion against the Roma and to reduce the unacceptable gaps between this population and the rest of society in education, housing, employment and health." In order to achieve this, governments were urged to: (a) reallocate resources; (b) elaborate national and regional plans in collaboration with social organisations and the Roma community, involving them in the decision-making and experience-sharing process; and (c) adopt an accountability approach to measure the real impact of their actions. More specifically, member states that endorsed the DRI reached the following conclusions during their 23rd International Steering Committee meeting in Zagreb in 2012: (1) the complexity of the problem requires that the final step in the project be effective transformation and implementation of fair and inclusive healthcare policies; (2) policies must be more sensitive to the values, discourses and narratives of Roma communities and implicate all the agents involved (e.g., citizens, social networks, researchers, government representatives and other

[5] Decade of Roma Inclusion 2005-2015 http://www.romadecade.org/

[6] Participating countries in the DRI: Albania, Bosnia and Herzegovina, Bulgaria, Croatia, the Czech Republic, Hungary, Macedonia, Montenegro, Romania, Serbia, Slovakia and Spain.

influential groups); (3) it is necessary to legitimise politically the Roma population, not only as service users, but also as political subjects that contribute to the health of society as a whole.

In this same vein, the World Health Organization's (WHO) programme Health 2020[7] emerges as a new framework for understanding public health in Europe, and as a response to the gaps in health created by the economic crisis. It draws attention to the need to support and promote participation, leadership and collaborative action between governments and civil society in order to improve the health and wellbeing of citizens, reducing health inequities and strengthening the public health system to be people-centred, universal, equitable, sustainable, and with quality. In order to reach these objectives, Health 2020 is committed to develop strategic thinking for: (a) implementing whole-of-government and whole-of-society approaches that consider health and wellbeing as a shared responsibility; (b) tackling inequities and the social determinants of health; (c) innovative leadership and capacity for health and development; and (d) citizen empowerment.

However, in 2010, the EC elaborated a report on the Economic and Social Integration of Roma in Europe (European Commission, 2010a) which made clear the progressive deterioration of Roma living conditions, notwithstanding the aforementioned policies. The general failure of these initiatives has been due to a wide range of factors such as the gap between planning and implementing measures; the weak inclusion of strategies and bottlenecks at the national, regional and local levels; the lack of economic resources and inadequate use of EU funds; the low participation of Roma community in the development and implementation of policies; the deficient support, commitment and leadership of institutions and stakeholders involved; and the low impact of the programme on public opinion and the media (European Commission, 2010a; McKee, Balanova & Steriu, 2007; Parekhm & Rose, 2011).

1.3. Roma health inequities as a 'wicked' problem

Due to its intersectional nature, Roma health inequities represent a "wicked problem" - that is, a problem that is extremely difficult to broach and solve (Rittel & Webber, 1979). Indeed, the fact that policies to that end are so few and so largely unsuccessful may be explained as follows (Commonwealth of Australia, 2007; WHO, 2012a):

- **Roma health has never been considered or defined as a social problem.** In fact, it is a problem that is difficult to define in a clear and durable way. Its nature and extension depends on who defines it –whether it is healthcare service providers, the communities themselves or policymakers—and not on objective and stable causes. The disagreement that exists among the agents involved in its definition does not derive from whether the analysis is wrong or right, but rather from the dimensions that are emphasised, underlined and prioritised.
- **The political concern around Roma health has not successfully taken form into effective policies on the ground but only at a rhetorical level**. Moreover, many of the policies have had unforeseen and even paradoxical consequences. This is due to the fact that the circumstances of the problem are unstable and different in every country. Furthermore, its solutions are not verifiable in terms of right and wrong, but rather in comparative terms: solutions that are better or worse than others. As a consequence, it must be accepted that the problem will never be completely solved.

[7] Health 2020 http://www.euro.who.int/en/health-topics/health-policy/health-2020-the-european-policy-for-health-and-well-being

- **The complexity of the problem does not derive from scientific but political and social difficulties.** As such, it does not require sophisticated resources, but agreements among social groups and commitment to solve the problem. In this sense, progress would imply changes in the lifestyles and conducts of agents and communities. Therefore, the motivation of agents to make sustainable changes in their conducts is of utmost importance.

1.4. Transforming Roma health policy through stakeholder collaboration

All these elements evidence the need to **find innovative strategies to actively engage all stakeholders** in the design, implementation, and assessment of Transformative Roma Health Policies (TRHP). Traditionally, many of the stakeholders have played a secondary role in the elaboration of health policies and strategic plans, tasks that were reserved exclusively to policymakers. The other agents have been summoned to legitimate and facilitate the implementation and assessment of these – a role which has proven insufficient for Roma health policies. Collaboration among different stakeholders must be part of permanent and proactive process of transformation to constantly shape the problem, as well as the strategies and actions implemented to solve it.

Transformative policy change refers to changes in policy that incorporate the views of multiple actors and resort to the best available evidence, while aiming to accommodate people's values and to give them real power to influence the decisions that most impact their lives (Nelson, 2013). Transformative changes in policy can benefit from evidence-based and discursive approaches. The former asserts that policy should be informed by research-based evidence (Pawson, 2006). The discursive approach, on the other hand, understands policymaking as a political and value-laden process that deals with choice of directions and, as a result, can bring advantage to some groups and disadvantage to others. This approach also highlights the need to understand discourse not as reflective of objective social problems but as a reality itself, which needs to be explained and taken into consideration (Fisher, 2003). Thus, achieving transformative policy change depends on three fundamental processes: (1) explicit and discussable problem framing; (2) citizen participation in policy formulation; and (3) allocation of resources necessary for policy formulation and implementation (Nelson, 2013).

Transforming healthcare policies to become more sensitive to diversity requires us to understand that engaging all stakeholders in policymaking is essential for the success of the process, but also that it is one of its greatest challenges. Contexts of diversity are complex settings characterised by uncertain and plural legitimate perspectives. Consequently, there is no single way of looking at particular problem and/or the expectation that one simple solution fits the needs and interests of all. Achieving transformative policy change requires that the various stakeholders participate in exchanging viewpoints and arguments within an empowering and organised participatory environment open to everyone and based on the values of effective partnership (e.g., reflexivity, respect for difference, mutual commitment and collaborative work) (Allen et al., 2013). The involvement of citizens in this process necessitates adequate allocation of resources as well as citizens' ability to take control of the resources they need to influence decision-making. Furthermore, stakeholder involvement in transformative healthcare policymaking needs to be implemented as a process of community mobilisation in building collaborative capacity among all stakeholders, leading to the development of shared understanding and collective commitment and action (De Freitas et al., 2014).

Community mobilisation refers to bringing people and organisations together in particular geographic area (e.g., a neighbourhood, a city or county, a region or sometimes an entire state) to partner up in defining a problem, identifying possible solutions, and working together to implement them (Fawcett et al. 2000). **Building collaborative capacity** is associated with promoting a sense of community and a culture of learning, also referred to as communities of practice, among partners, in which individual members gain understanding, voice, and influence over decisions that affect their lives (Florin et al., 2010; García-Ramírez et al., 2009). **Communities of practice** are groups working together on enterprises with common values. The sense of community of practice in action allows members to produce a collective commitment to identify needs and lead initiatives by means of participation, dialogue, deliberation, and self-determination (García-Ramírez et al., 2009).

All stakeholders involved are part of the solution of the problems –or will be part of the failure of the policies that attempt to address these problems. This entails the development of structures to ensure that the needs of the different agents involved are covered in terms of mutual gains, reciprocal benefits, and a fair distribution of responsibilities (e.g., implementation, costs, responsibilities, time, and personal commitment). The relationships established among the stakeholders that define and implement policies and practices are central elements in social ecology. Any variation in the nature, intensity, range and authenticity of these relationships affects the processes in which they take part, as well as the overall results. As a consequence, health and healthcare policymaking also requires a particular way of sharing and communicating the activities that are carried out. Disregarding the way in which actions are assessed and communicated may jeopardise the credibility of the efforts devoted to implementing those actions.

This report is the result of the work done by the Spanish consultants to tackle the challenge of ensuring the equity of health policies for the Roma population, adopting the viewpoint of the different stakeholders involved while developing their capacity for collaboration and building shared understanding of the problem. Following the model proposed in *Guidance for Uncertainty Assessment and Communication* (Petersen et al., 2012), this report consists of the following chapters:

- **Framing the problem**. This section describes how the problem is shaped from the different perspectives and information levels offered by the DRI, the Open Society Foundation and the World Bank among others. It presents a general overview of the national and foreign Roma communities in Spain, as well as he social determinants of health inequities that they suffer. Finally, it also describes the current policies that the EC and member states have agreed as responses to Roma health inequities and challenges.
- **Building and releasing collaborative capacity to transform.** This section offers an inventory of the visions that have contributed to this report in shaping the problem. It includes all the documentation obtained from the desk review process as well as the viewpoints of different stakeholders that composed the coalition created for this report. The resulting information were analysed following the Roma Integration Policy Index (RIPEX), a tool composed of categories and indicators proposed by the different stakeholders, Equi-Health, the WHO, and the Migrant Integration Policy Index (MIPEX).
- **Promoting shared understanding from evidences and stakeholders.** In this section, we provide a chain of evidences expressed in the RIPEX tool as a result of the shared understanding among stakeholders and the desk review findings. The results are presented

following the RIPEX categories: (a) Entitlement to healthcare; (b) Access to the healthcare system; (c) Responsiveness of healthcare services; and (d) Achieving and sustaining change.

- **Planning the future.** This final section shows the principles that should guide the development and implementation of priorities in TRHP through different tools based on methodologies for innovation and new technologies. Special attention is given to the development of a Roma Tool Box.

2. FRAMING THE PROBLEM

When we are dealing with a 'wicked' problem, one of the first challenges that we must tackle is defining and framing the problem (Nelson, 2013; Petersen et al., 2012). In order to do so, we must pay attention to: (a) the existing definitions or frames of the problem—including likely definitions and points of view of the researchers, the end-users, and all stakeholders; (b) interconnections with other problems; (c) other relevant aspects that have not been addressed before; (d) the role of the study in the policy process; and (e) the way in which the study connects to previous studies on the subject.

The Roma health problem is shaped from diverse perspectives and levels of information provided by different organizations such as the DRI, WHO, EC, the Open Society Foundation, the World Bank and the Ministry of Health of Spain. In this task, it is important to highlight the special role of the Roma associative movement and its increasing international and European presence since the First World Romani Congress in 1971 and the involvement of EU member states in redefining the problem and demanding new acting mechanisms. This section offers a general overview of the health problems of the national and foreign Roma population in Spain, providing information about the background and some of the characteristics of this population. This is followed by a description of the health inequities, as well as the social factors that determine these. Finally, this section outlines the current challenges in Roma health and discusses the European response to this problem.

2.1. National and foreign Roma in Spain

According to official data, the population of Spain currently stands at 47,129,783. Out of the total population, between 700,000 and 970,000 (i.e., 1.5-2.1%) are Roma, which means that it is the main ethnic group in the country (Fundación FOESSA, 2008). Most of the national Roma people in Spain live in Andalusia, Catalonia and Valencia. It is estimated that between 170,000 and 350,000 national Roma live in Andalusia, whereas between 40,000 and 60,000 live in Catalonia (Laparra, 2011). The total number of both national and foreign Roma remains unknown. There are no censuses or official statistics regarding ethnic origin or religion despite the fact that the Organic Law 15/1999 of Protection of Personal Data[8] and the European Directive 2000/43/EC on implementing the principle of equal treatment between persons irrespective of racial or ethnic origin[9], encourage collecting ethnic data in order to improve the quality of healthcare assistance and the wellbeing of those affected.

The Roma population is diverse and heterogeneous, with clear differences between national and foreign groups. Nevertheless, there are also commonalities between them. The foreign Roma population shows the highest levels of mobility, although this must not be understood as *nomadism*, since in many cases they are forced to move against their will. As a matter of fact, they are often expelled from settlements, or they find it difficult to rent properties, either because they go back to their countries for short periods of time, or because they do temporary jobs in different locations (Laparra, 2007). Also, both groups have the largest population of children under 16–nearly a third of the total population—and the lowest percentage of people over 65. This reveals Roma

[8] Organic Law 15/1999 of Protection of Personal Data https://www.boe.es/buscar/act.php?id=BOE-A-1999-23750
[9] COUNCIL DIRECTIVE 2000/43/EC of 29 June 2000 implementing the principle of equal treatment between persons irrespective of racial or ethnic origin http://eur-lex.europa.eu/legal-content/ES/ALL/?uri=CELEX:32000L0043

population's capacity for rapid growth: it enjoys high birth rates (although progressively declining in recent years), decreasing death rates, and a higher life expectancy (although lower for males) (Laparra, 2011; Ministry of Health, Social Services and Equality, 2012a). Women outnumber men in both age groups, higher and their role, at least within the national population, is central for the family and the community, becoming a driving force, acquiring social relevance, leading change and modernisation within the Roma community (Esparcia, 2009). Some cultural values and customs are similar in both populations, such as the family and social structures: their social organisation is based on communities where the extended family plays an important role (Laparra, 2007; Mendez, C., 2007). In contrast, the majority language of foreign Roma is Romani, whereas national Roma speak the *Caló* variant of Romani and Spanish (Ministry of Health, Social Services and Equality, 2010). These similarities and differences are also present in more specific contexts, such as health inequities and the social factors that determine these.

2.2. Roma health inequities and social determinants

National Roma health has improved in recent years thanks to the implementation of universal healthcare, the rehabilitation of marginal areas, housing improvement, and the expansion of compulsory schooling (Fundación Secretariado Gitano, 2012; Laparra et al., 2012). In spite of all this, work still needs to be done in order to reduce the social determinants and health inequities between the mainstream population and the Roma, and between the national and foreign Roma.

The most important factor that determines directly or indirectly Roma health is socioeconomic status. Around 77% of the Roma population in Spain live in relative poverty, and 37.5% live in extreme poverty. These percentages increase when dealing with the European Roma community: if we extrapolate their countries' statistics, 37.2% of Roma Bulgarians live in relative poverty and 80.1% live in extreme poverty; whereas in Romania, it is 43.1% and 68.8% respectively (Fundación Secretariado Gitano, 2012). These socioeconomic differences give rise to serious inequalities regarding education, housing, health and employment, inequalities that are even greater for foreign Roma coming from Eastern Europe, due to the chronic poverty and social exclusion that they suffer in their own countries (Laparra, 2012; Rodríguez-García & San Román Espinosa, 2007).

Nevertheless, socioeconomic status is not the only factor that influences social inequalities. It is well-documented that Roma health is worse than that of the rest of the population in all age segments (Ministerio de Sanidad, Política Social e Igualdad, 2010). This may be due to additional determinants, such as labour market segmentation, gender roles, the concept of health and other cultural values of the general population rooted in social persecution and stigmatisation. These socio-cultural determinants prevent equal access to and adequate use of the NHS, increasing the health vulnerability of the Roma groups. For example, they often live in crammed and insanitary dwellings in segregated areas with structural deficiencies and poor urban planning, far from public services. There are also other determinants related to the health system itself and its services, such as accessibility barriers or the lack of intercultural competence of its centres and providers. Furthermore, health inequities are intrinsically related to inequities in other fundamental aspects for human development. For instance, the high rates of school absenteeism and school failure among Roma children lead to high illiteracy rates among adults, which at the same time determines their level of employability, their opportunities to access decent housing, as well as the information and skills necessary to successfully manage their health (Laparra, 2007, 2011; Parekh & Rose, 2011).

As a consequence of all these inequities, the national Roma population has a lower life expectancy, more negative view of health, worse eye and ear health, and more traffic and domestic accidents. Some sectors of the infant population have not received their vaccinations, do not get regular paediatric check-ups and have a deficient or unbalanced diet, which may lead to obesity, worse dental health, diabetes, and the like (La Parra, 2009; Laparra, 2007, 2011). Regarding adults, they make deficient use of preventive services and are more prone to suffer from silent diseases such as cardiovascular, bone, joint and chronic diseases. In particular, women tend to suffer from obesity; they do not do gynaecological prevention, which causes related problems, such as early pregnancy; and they suffer more mental health problems (e.g., stress, depression, anxiety and so forth) than that of the rest of the Spanish population (La Parra, 2009; Laparra, 2007, 2011; Ministerio de Sanidad y Consumo & Fundación Secretariado Gitano, 2007).

Although there is no reliable information about the health of foreign Roma living in Spain, several inferences may be derived from the data obtained in their countries of origin (Hajioff & McKee, 2000; McKee, Balabanova & Steriu, 2007; Parekh & Rose, 2011). Their life expectancy is 10 to 15 years lower than the rest of the population in their countries, with higher mortality rates among young adults and children. Many of these suffer from malnutrition and infectious diseases such as tuberculosis, hepatitis, polio and measles, as well as alcohol and drug abuse. More than 84% of the population live under the poverty threshold and almost 80% are unemployed. Only 50% have access to running water and 15% have hot water. Also, the number of people with psychiatric or mental disorders is six times higher than in the rest of the population. Moreover, traditions such as big families and early marriages lead to teenage pregnancies and increase child vulnerability. Finally, the lack of healthcare centres in segregated areas and the absence of public transport make it more difficult for Roma people, including children, to get the necessary documents to register with and access healthcare system.

In recent years there has been an increase in the mobility of citizens from Eastern Europe (McKee, Balabanova & Steriu, 2007). This, together with the decline of European economy, has become one of the main challenges that need to be dealt with in order to abolish the gap between foreign Roma health and that of the rest of society. In 2007, Bulgaria and Romania formalised their EU membership, gaining freedom of movement across the countries of the EU and the right to work in the European labour market. These events, together with a waiver visa policy for Wester Balkans' citizens, have been the cause of an increase of foreign Roma population in Spain, and it is expected that it will continue to grow in the short and medium term. It is also likely that most of these immigrants will be of Roma origin, since many of them are forced to leave their countries due to marginalisation and poverty. At the same time, the rise of xenophobic policies in certain EU member states[10][11][12], have made of Spain preferred destination for many of them since it has one of the largest Roma populations in Europe and, in recent years, it is also one of the countries in the EU with more inclusive policies towards Roma.

[10] El ministro del Interior francés arremete contra los gitanos, *El País,* September 2013
http://internacional.elpais.com/internacional/2013/09/24/actualidad/1380022331_876484.html
[11] Miles de gitanos protestan en Roma contra la xenofobia, *El País,* June 2008
http://internacional.elpais.com/internacional/2008/06/08/actualidad/1212876007_850215.html
[12] París detiene y deporta a una alumna gitana durante una actividad escolar
http://internacional.elpais.com/internacional/2013/10/14/actualidad/1381773587_389978.html

At the same time, foreign Roma arrivals have become a challenge to human rights, and a possible risk for public health, since when these Roma get to Spain in very precarious conditions and with no chances of finding a job, many of them are forced to live in shanties, in temporary and unsanitary settlements where the same subhuman conditions of their own countries are replicated. Consequently Roma people are subjected to extreme forms of discrimination and segregation, and are often confined to ghettos with no access to social or healthcare services. The precariousness of their settlements, together with their extreme poverty, makes them vulnerable to many health risks. Furthermore, the situation is getting worse now, since constant evacuations lead families to stop devoting their time and efforts to build safer shanties and settlements, as they know these will be soon destroyed. They sleep in tents that are packed up in the morning, when they leave the place in order to go begging or collecting scrap metal for the day. Persecuted and stigmatised for their vulnerability, their precarious health condition contributes further to their marginalisation, creating new risks and suffering.

2.3. The EU response to Roma health inequities

The progressive deterioration of health conditions and access to health services of Roma population, together with the failure of policies aimed at reducing these inequities, drove the attention to the need of fostering further collaboration among EU member states. Thus, in April 2011, the EC adopted the *EU Framework for National Roma Integration Strategies (NRIS) up to 2020* (European Commission, 2011), by which EU countries committed to (a) complementing and reinforcing the EU's equality legislation and as well as supporting policies and authorities at national, regional and local level in monitoring, sharing and strengthening approaches to Roma health, education, employment, and housing; and (b) building a coherent network to promote dialogue and participation among key stakeholders and to delineate strategies and interventions to support capacity building and cooperation in order to address the specific needs of the Roma.

By 2012, each EU member state had to elaborate a National Strategy included in the document entitled *A First Step in the Implementation of the EU Framework* (European Commission, 2012). Later in 2013, the EC drafted the document *Steps Forward in Implementing NRIS* (European Commission, 2013), which established the necessary requirements for each EU country to achieve Roma inclusion in the different areas mentioned above. Regarding health, the NRIS's aim is to make possible for Roma people to access quality healthcare, preventive assistance and social services in the same conditions as the rest of the population, placing the focus on women's and children's health. Also, it sought the participation of qualified Roma in their communities' health programmes. More specifically, EU members were advised to: (a) extend health and basic social security coverage and services; (b) improve the access of Roma, alongside other vulnerable groups, to basic, emergency and specialized services; (c) launch awareness raising campaigns on regular medical checks, pre- and postnatal care, family planning and immunization; (d) ensure that preventive health measures reach out to Roma, in particular women and children; and to improve living conditions with focus on segregated settlements (European Commission, 2012).

The Spanish NRIS was developed by the Ministry of Health, Social Services, and Equality (Ministerio de Sanidad, Política Social e Igualdad, 2012b). This document adopted the objectives and suggestions made by the EC, aiming to improve Roma health status and to reduce the social inequalities in health with differentiated targets for adults and children. Concerning adults' health, the targets are to improve the perception of health status of the Roma population and reduce

traffic accidents and smoking. Special attention is also given to reducing obesity among women and to reducing the number of women who have never gone to the gynaecologist. In relation to the child population, the NRIS aims to reduce the number of children suffering domestic accidents and increase oral healthcare. In 2014, an Operational Plan (*Plan Operacional;* 2014-2016) was approved in order to implement lines of action to achieve the objectives proposed by the Spanish NRIS. These are: (a) promoting policies and actions aimed at reducing health inequalities, (b) reorientation of health services towards equity, (c) fostering health promotion throughout the life course, (d) establishing mechanisms to ensure the impact on Roma health, (e) promoting Roma participation, (e) promotion of inter-sectoral work, (f) support and promotion of diversity training, and (g) cultural adaptation of resources (Ministerio de Sanidad, Política Social e Igualdad, 2013a).

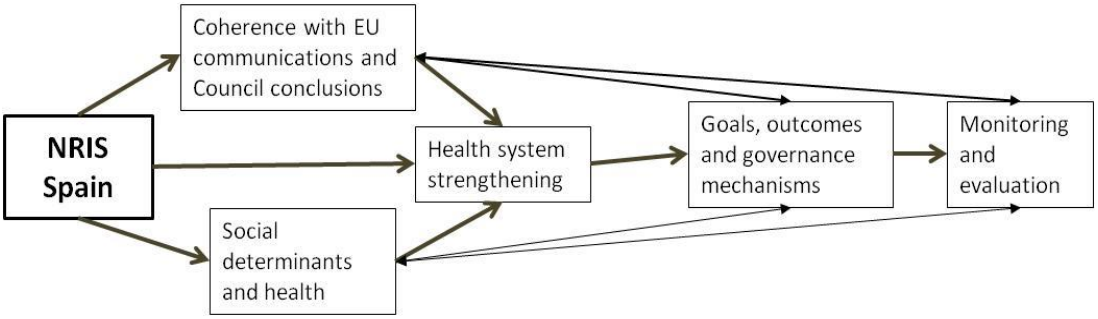
3. BUILDING COLLABORATIVE CAPACITY TO TRANSFORM

As discussed above, transformative policy change refers to policy changes that are rooted in the available scientific evidence together with the vision of multiple stakeholders and their values, thus providing real capacity to influence in the decision making process. According to the principles stated in the introduction, this requires the new policies to be based both on an evidence-based approximation—that is to say, the policies must be informed by evidence-based scientific research; and on a discursive approach—which means building policy as a process based on the values and participation of all stakeholders (De Freitas et al, 2014; Nelson, 2013). In this section, we first provide the methodology employed in this report: a systematic review of the literature and the creation of a coalition. After that, we present the tool used to analyse and discuss the collected information.

3.1. Evidence based approach: systematic review

The desk research has been an on-going process throughout the preparation of this report. It was organized following the Community Guide on Systematic Review Methods[13]. This consisted of literature review, legal review and policy research collecting data and combining information from various sources in order to obtain the most comprehensive overview of the foreign and national Roma population in Spain, and more specifically in the AACC of Andalusia and Catalonia. We focused our search on information on the period between 2005 and 2013. To carry out the desk research we first searched the international databases MEDLINE, PubMed and Google Scholar using keywords such as "health," "Roma," "gypsy," "Spain," "policies," "strategies" both in English and Spanish. Next, we did a comprehensive search using websites pertaining to departments of health—national and regional, different Roma CSOs' websites, sources of information provided by Equi-Health, and so on. Out of the total of publications found, we selected the most relevant documents (Annex 1) that fit within the analytical framework (Figure 1) proposed by the WHO's Potential Criteria for the Review of the Health Component of the NRIS (WHO, 2012a).

Figure 1: Analytical framework to assess evidence based approach



3.2. Discursive approach: key stakeholder involvement

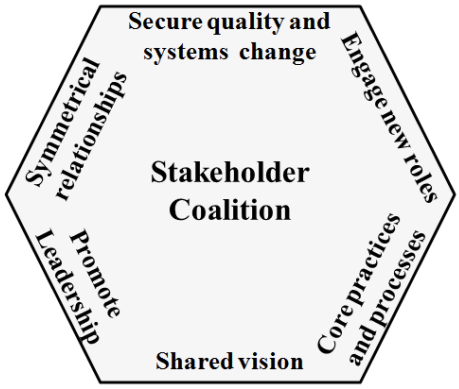
To carry out the discursive approach a coalition or stakeholder network was constituted in order to generate collaborative capacity building among them. Collaborative capacity allows us to study stakeholder networks as multicultural empowering settings (Box 1).

[13] Community Guide on Systematic Review Methods http://www.thecommunityguide.org/about/methods.html

Box 1: Stakeholder network as multicultural empowering settings

An empowering community setting is understood as a community-based structure which facilitates development of the members, community betterment and positive social change (Paloma, Garcia-Ramirez, de la Mata & AMAL, 2010). These settings are characterized by the following features:

Figure 2: Stakeholder network as multicultural empowering settings

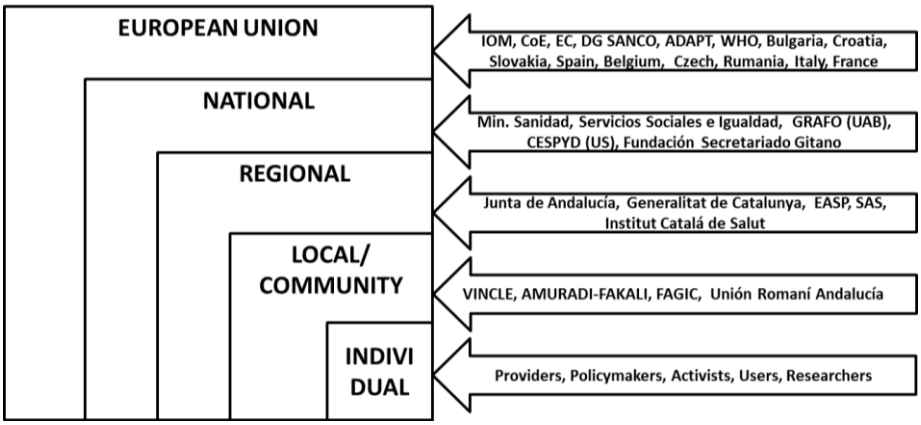


1. **Capacity to adopt a shared mission,** embracing equality and diversity as values; recognizing diversity of origin, cultural and linguistic experiences; assuming models of services and care based on the individual; acknowledging the specific needs generated by being of minority status in European society; including reciprocity, compromise, and collaboration as strategic principles.
2. **Adaptation of services and organizational processes** (policies, standards and procedures) to the needs of the multicultural collective group; probing and sharing evidence and best practices that integrate knowledge, the view of multicultural populations users of services; and developing evidence-based practices.
3. **Promote horizontal and reciprocal relationships,** by including users of services and representatives from other community agencies in the decision making process in the organizations; establishing strong partnerships with universities; and fostering the exchange of ideas and multicultural events among multicultural communities, community settings and providers.
4. **Create capacity to engage different roles**, encouraging diversity among members; identifying cultural mediators, community gatekeepers, volunteers, and including spiritual and cultural healers.
5. **Promote leadership** among members who are pluralistic, multicultural individuals, capable of equally representing the needs and views of all constituents and relate with ease with multicultural communities.
6. **Secure quality and systems change**, instead of pursuing a quick fix approach to addressing changes in services, focus on pursuing long-term social change, seeking to maintain the quality of services and protecting changes to policies and practices that support multicultural populations.

To assure the stakeholder participation in the elaboration of the report, the Spanish Equi-Health coalition included representatives of organizations with relevant role in the field of Roma health (Figure 3; Annex 2). Assuming a systemic view, policymakers, managers, healthcare providers and end-user representatives were chosen. Other participants include members of research groups and representatives of institutions, organizations and associations working in healthcare for Roma

people in Andalusia and Catalonia. Moreover, and due to its European context, several European stakeholders have contributed to this report, including representatives of the IOM, the EC, the ADAPT project, which belongs to the European Cooperation in Science and Technology research network (COST); and the WHO. Stakeholders from other countries involved in the Equi-Health action (i.e., Bulgaria, Croatia, Slovakia, Belgium, Czech Republic, Romania, Italy, and France) also took part.

Figure 3: Spanish Equi-Health Coalition



The discursive approach was organized in the following way: First, two initial coalition meetings were organized in Sevilla and Barcelona in February and March 2014—respectively—in which the Equi-Health project was presented, key stakeholders were invited to participate both in the coalition and the report, and first discursive data was collected. After that, stakeholders were individually interviewed during March and April, 2014. National consultants drew the interview guideline (Annex 3) from the indicators set out in the Terms of Reference (ToR) of Equi-Health (Annex 4). In total, 33 interviews—15 in Andalusia and 18 in Catalonia—were conducted by five researchers. These were recorded under the informed consent of the interviewees, transcribed, and qualitative analysed by two researchers using the software ATLAS.ti 5.0 and following the assessment categories and indicators developed by this report (i.e., the RIPEX; see next section). Later in October and November, two new coalition meetings were organized—again in Sevilla and Barcelona—to present the preliminary findings of the report. Stakeholders were also asked to provide feedback on the work done as well as to propose and discuss recommendations and priorities for planning the future in Roma health. This new information has also been incorporated in our report (see chapter 5).

3.3. RIPEX: an NRIS assessment tool

A new tool, **the RIPEX (Roma Integration Policy Index)**, was developed in order to analyse and integrate the findings of the stakeholder interviews and coalitions, as well as those obtained in the desk review. This index was promoted by the network set up in Equi-Health to assess and contrast how sensitive health policies are towards the Roma population. It is composed of a series of categories and indicators selected from: (a) the WHO's assessment recommendations for the health branch of the NRIS, (b) the Migrant Integration Policy Index (MIPEX), (c) those required by the IOM in the Equi-Health project, and (d) the suggestions made by the stakeholders.

The WHO has elaborated a list of indicators to assess the health content of the NRIS (WHO, 2012a). The criteria used can be grouped in five different areas: (1) coherence with the EU's and the Council of Europe's communications; (2) strengthening the health system; (3) social determinants of health; (4) objectives, results and governing mechanisms; and (5) monitoring and assessment. According to the document elaborated by the WHO's international committee, these criteria are based on the EU Communications and Council Conclusions on Roma Inclusion, the Communication "Solidarity in Health: Reducing Health Inequalities in the EU" and recommendations made by the Council of Europe and the Open Society Foundation's Roma Health Project. They reflect the policy guidance and evidence base represented by sources such as Article 12 on the right to health of the International Covenant on Economic, Social and Cultural Rights; the work of the Commission on Social Determinants of Health; the emerging findings of the Task Group on Disadvantage, Social Exclusion and Vulnerability of the WHO-commissioned European Review on Social Determinants and the Health Divide; and the Health 2020, among others (WHO, 2012b, p.1).

The MIPEX[14] **(Migrant Integration Policy Index)** is a fully interactive tool and reference guide to assess, compare, and improve integration policy. MIPEX measures integration policies in all EU Member States plus Norway, Switzerland, Canada and the USA up to 31 May 2010. Using 148 policy indicators, MIPEX creates a rich, multi-dimensional picture of migrants' opportunities to participate in society by assessing governments' commitment to integration. By measuring policies and their implementation, it reveals whether all residents are guaranteed equal rights, responsibilities and opportunities. MIPEX draft health policy indicators are being elaborated in collaboration with the network ADAPT, whose aim is to develop a series of changes to adapt European health systems to the demands of a multicultural society, placing emphasis on vulnerable groups. It focuses on four sources of variation: (1) entitlement to healthcare services; (2) policies to facilitate access; (3) responsive health services; and (4) measures to achieve change. Regarding entitlement, it involves coverage for different groups, including the most vulnerable ones, affordability and co-payment. With regard to policies to facilitate access, it includes availability of information for providers about the rights of minorities, mechanisms to facilitate communication, measures to reduce the obstacles in access to healthcare and the use of cultural mediators. With respect to responsive healthcare services, it focuses on methods used for interpretation, the creation of culturally competent services, and the involvement and participation of users in the provision of services. Finally, the measures to achieve change include support for research and the adoption of the "health in all policies" approach.

Through the Equi-Health ToR (Annex 3), the IOM includes a series of indicators to assess the NRIS. In the case of Spain, these were: (a) barriers in the access to basic, emergency and specialized healthcare services for Roma; (b) social security coverage and existing local solutions to low coverage for Roma communities; (c) process of development and revision, the implementation of national commitments, evaluation/monitoring mechanisms, funding and sustainability, involvement of local authorities and civil society organizations; (d) how national strategies and actions relate to and contribute to EC policies on health inequalities, with particular attention to Europe 2020; and (e) Roma health mediators programme (e.g., implementation, challenges, monitoring, evaluation, sustainability and institutionalisation).

[14] Migrant Integration Policy Index (MIPEX) www.mipex.eu

Consequently, the final **RIPEX** tool consisted of the following categories and indicators - discussed by the stakeholders in the development of this progress report:

Entitlement to healthcare

- *Requirements for obtaining entitlement:* this indicator focuses on the formal and informal requirements for national and foreign Roma to access the healthcare system and its services. It includes aspects related to the Health Card application process and other requirements related to forms of identification, registration, and so forth.
- *Co-payments:* this indicator deals with the payment system that the Roma population has to use to have access to medical attention. It examines the prevalence of out-of-pocket payments and the cases of exemption from payment (such as low income or chronic diseases).
- *Coverage:* it is referred to the list of services to which the Roma population has access. It distinguishes between healthcare coverage for national Roma and that for foreign Roma.

Access to healthcare system

- *Accessibility barriers*: this indicator determines the different barriers that hinder national and foreign Roma's access to the NHS and its services. These barriers may be related to the culture of the Roma community or derived from the system itself and its providers, among others.
- *Policies to suppress accessibility barriers*: policies developed and implemented by local, regional or national plans intended to tackle accessibility barriers.
- *Adaptation strategies to suppress accessibility barriers*: strategies are specific actions developed by providers of healthcare centres or CSOs to eliminate the barriers that hinder the Roma population's access to healthcare.
- *Roma health mediation*: this indicator includes aspects related to the tasks of health mediators working with Roma people. It deals with the training of providers, the collaboration of Roma patients with healthcare services, and so on.

Responsiveness of healthcare services

- *Health inequalities identified in the NRIS*: including inequities described in the Operational Plan 2014-2016 and their critical review.
- *Policies to make healthcare services more responsive*: it includes aspects related to the training in cultural competence of service providers.
- *Adaptation strategies of healthcare services and providers*: these are the measures adopted by healthcare providers and some health centres to adapt to the characteristics and needs of the Spanish and foreign Roma population.

Achieving and sustaining change

- *The political and economic context of the NRIS*: this indicator assesses the healthcare system's capacity to achieve the objectives of the Operational Plan of the NRIS. The focus is placed on how these objectives are shaped by the current restrictions imposed on the NHS.
- *Associationism, participation and collaboration of the national and foreign Roma community:* it describes the relationships between national and foreign Roma, Roma associationism and participation, as well as the collaborative relationships among different organisations and how these contribute to improving Roma health.

- *Collaborative work among multiple stakeholders:* this indicator outlines the synergies among different organisations and how these contribute to improving the health and wellbeing of the Roma community. These organisations include local, regional and national institutional bodies, healthcare and academic institutions, Roma associations, social organisations and NGOs.
- *Promoting inter-sectoral action*: this indicator examines the synergies between the different programmes intended to promote and improve the use of healthcare services within the framework of the NRIS.

4. PROMOTING SHARED UNDERSTANDING TO TRANSFORM ROMA HEALTH POLICIES

In order to take stock of all the challenges and recommendations obtained through the stakeholder interviews and desk research, the chain of evidences will be presented following the RIPEX structure:

4.1. Entitlement to healthcare

The NRIS is based on the idea that healthcare assistance in Spain is free and universal for all those who live in the country, regardless of their ethnic origin, their legal or social status. This is the starting point for the Operational Plan of the NRIS for forthcoming years: "for the universalization of the whole system, the priorities are (a) counselling on lifestyles in primary care [...] during pregnancy and lactation [...] and the promotion of the emotional wellbeing of the infant population" (Ministerio de Sanidad, Política Social e Igualdad, 2013a, p. 28). National Roma are entitled to healthcare by virtue of the same legislation that entitles the rest of the Spanish population. In the case of foreign Roma from EU and non-EU countries, the laws that apply are those addressed to the foreign population. However, it is important to outline the healthcare legislative changes that have taken place in Spain since 2012 at the hands of the Government of the Popular Party (*Partido Popular)* and which represent the main milestones for the implementation of the NRIS in Spain (Box 2).

Box 2: Latest changes in the Spanish legislation

(1) Article 43 of the Spanish Constitution of 1978 establishes the right to health protection and healthcare assistance of all citizens. Similarly, Articles 1 and 3.2 of the Law 14/1986 on General Health entitles all Spanish and foreign citizens who reside in Spain, applicable to all the Spanish population, to health protection and healthcare assistance. Since then, health insurance for Roma people expanded until they were entitled to healthcare in the same conditions as any other Spanish citizen (Fundación Secretariado Gitano, 2012; Laparra, 2007).

(2) This process of universalisation was shaped further with the Law 16/2003 of Cohesion and Quality of the NHS, whose aim was to put forward a new definition of healthcare entitlement, where users are no longer insured by the Social Security System but beneficiaries of the NHS. Article 3 of this law established entitlement to health protection and primary care for: (a) all Spanish and foreign people in Spanish territory; (b) nationals from EU member states that hold agreements with Spain to entitle them to healthcare assistance; and (c) non-EU nationals who are entitled by virtue of laws, treaties and agreements subscribed by both parties.

(3) In 2012, the Government of the Popular Party modified the law by approving the RDL 16/2012 on urgent measures to guarantee the sustainability of the NHS. This decree represents a backward movement in the universalisation of the NHS, thus restricting the entitlement of national and foreign Roma as it has modified Article 3 of the Law of Cohesion and Quality of the NHS, eliminating the concept of universal healthcare in favour of healthcare insurance. These changes may affect the implementation of the NRIS and its Operational Plan in Spain. According to this decree, only the following groups are eligible for healthcare insurance: (a) workers affiliated to the Social Security System; (b) pensioners of the Social Security System; and (c) recipients of jobseeker's allowance and unemployment benefits. Spanish nationals and nationals from EU member states who do not

belong to any of these groups may be eligible for healthcare insurance if they can prove that their income does not surpass certain established limits. This decree also extends pharmaceutical co-payment to prosthetic treatments, dietary products and ambulance services. In the case of foreign Roma, the RDL 16/2012 hinders their access to health services because it limits the entitlement to healthcare of people who are not resident in Spain. Therefore, and in spite of their being EU citizens, these people's entitlement to health has been considerably restricted, and they are doubly marginalised for being both Roma and immigrants before the law. This decree has also generated obstacles for the national population, as it has eliminated the entitlement to health of those above 26 that have not contributed to Social Security, it has toughened the requirements for disability allowance, it has imposed stricter forms of control of access to medical assistance by means of the Health Card, and it has implemented a pharmaceutical co-payment system.

(4) For those who are excluded by this decree, including irregular and unemployed immigrants, the Government passed the RDL 576/2013, turns the NHS into a sort of health insurance company that charges EUR 60 a month for users under 65, and EUR 157 for those over 65. These fees may be raised by the autonomous communities or in accordance with the cost of services.

In the same line, Andalusia approved an instruction of the D.G. de Asistencia Sanitaria y Resultados en Salud of Andalusian Healthcare Service (SAS) intended to recognise and secure entitlement to healthcare assistance for irregular immigrants and people with no resources. This instruction establishes that medical coverage for these people will be the same as for those who are covered by the system, that is, they will have access to all the services offered by the SAS. This entitlement will be valid for extendable one-year periods. Furthermore, pharmaceutical co-payment will be 40 per cent for people under 65, and 10% for those over 65. To benefit from these measures, applicants must meet the following requirements: (a) they must be irregular immigrants; (b) they must not come from any of the EU member states, the European Economic Area or Switzerland, or from non-EU countries that have signed agreements with Spain regarding healthcare assistance; (c) they must not be insured by or beneficiaries of the NHS or any other health system; (d) they must be over 18; and (e) they must not have economic resources—although the instruction does not specify thresholds. Also, the documentation required is: (a) an application form; (b) although no form of identification is required, the information provided must be truthful and is liable to be checked; (c) if the applicant has an old Health Card, it should be produced to facilitate the application process; (d) in the case of EU citizens, it is necessary to produce a document issued by their countries of origin confirming that transferral of entitlement does not apply in this case.

However, although the Instructions in Catalonia and Andalusia have entitled many excluded people to healthcare assistance, these measures have not prevented the deterioration of the NHS in Spain.

There are several evidences collected in international and national reports which emphasize the negative consequences of these changes affecting both national and foreign Roma populations, and creating barriers to the effective implementation of the NRIS (Casino, 2012). Due to their high levels of unemployment, informal economy, and poverty, national and foreign Roma populations have been particularly hard hit by the financial crisis. Indeed, it is the poorest people and those who rely more heavily on public services that are more seriously affected by government cuts. In this regard, there is evidence of direct relationship between the loss of purchasing power of these families and an increase in health problems derived from malnutrition (e.g., gastroenteritis and growth problems and so on), poor sanitation, overcrowding and the impossibility of healthy shopping,

paying for hot water or paying the rent (Fundación Secretariado Gitano, 2013). Economic problems also bring about worse mental health (e.g., stress, depression, anxiety and so forth), especially for women with work overload and family obligations.

At the same time, the lack of material, human, and economic resources derived from cuts and the privatisation of services also gives rise to a series of consequences, such as: (a) the closure of primary care health centres (PHC) and specialised services near marginalised communities, making it more difficult for these to receive assistance and monitoring; (b) the reduction of and subsequent strain put on shifting workforce; (c) staff shortage and their lack of cultural sensitivity due to professional burnout and work overload; and (d) new pharmaceutical co-payments. All this has increased the number of people that demand medical assistance while it has also limited their rights and opportunities to access healthcare services, to the point that sometimes it is not possible to assist them (Fundación Secretariado Gitano, 2013).

As has been shown, the RDL 16/2012 strictly regulates access to healthcare service through the Health Card. Free access is only granted to emergency cases, pregnant women and minors. Without a Health Card, it is not possible to arrange appointments, to be transferred to specialised services or to follow certain protocols. Some stakeholders agree that this procedure is simply a thinly veiled excuse to deny medical assistance, since primary care can be easily offered without a card, and it is specialised treatment and prescriptions that are more problematic in this sense:

"I can order blood tests and other things, but I can't prescribe them medicines because they are not in the system."
(Healthcare provider1)

However, applying for a Health Card involves–together with all the legal requirements mentioned above- several bureaucratic procedures and additional documentation that are further barriers for the Roma population, especially foreign Roma, who do not have the necessary resources to navigate the system or to certify that they are unemployed or poor. For example, to register in the census of the community, many city councils ask for information regarding family income, rental agreement, etc.- impossible to provide for people who sublet or occupy flats or those who live in shanties or in caravans. Also, they need to produce some form of identification such as an ID card or a passport, which foreign Roma do not generally have, have lost, or have let it expire:

"They are not undocumented immigrants in the sense that they don't have a visa, but in the sense that they don't have any documents at all. That is, we know their names because they tell us. We don't have any information about the family structure that they say they have."
(Policymaker1)

In the case of foreign Roma, they must go to their respective consulates to get some form of identification or official documents to prove that they are not insured in their own countries. However, they are often ignored or unduly charged:

"We have this problem with Roma population, mainly Romanian, which are ignored by their consulate (...). Sometimes the consulate "charges them" for the authentication of these documents; a thing that shouldn´t be doing since other consulates of richer countries don´t do it."
(Policymaker3)

The cynicism of all these requirements is made evident when dealing with a population whose social determinants are precisely the fact that they do not have stable housing, that they live in conditions of extreme poverty in precarious settlements, that they have low education level and that, in the case of foreign Roma, they come from highly dysfunctional, broken homes. All the bureaucratic procedures that they have to go through to prove that they are poor, that they have neither a place to live or nor a steady job require a degree of specialisation and skills difficult to find in person with this profile. All this creates additional barriers that hinder further the national and foreign Roma population's access to the NHS and its services.

Box 3: Highlights of entitlement to healthcare

The NRIS in Spain and its Operational Plan are based on the universalisation of the NHS, enabling every Roma and any other citizen to access and enjoy their right to health. However, the latest changes (e.g., RDL 16/2012) in the legislation and the consequent cuts in the funding of the NHS have dismantled its core elements that characterized it for being universal, public and free. The main threats for the entitlement to healthcare are listed below:

- The new insurance-based healthcare model affects both national and foreign Roma. However, it has worsened the low socio-economic conditions of most vulnerable people, especially the foreign Roma. Co-payment is not an option for Roma people living below the poverty line even when they are entitled to healthcare services.
- There is direct relationship between the loss of purchasing power of these families and an increase in health problems derived from malnutrition and mental health problems.
- The cuts on the NHS' material, human and economic resources and the privatisation of services have given rise to consequences (e.g., closure of PHC and specialised services, staff shortage with lack of cultural sensitivity and/or burnout and work overload, co-payments)
- Applying for a Health Card involves bureaucratic procedures and additional documentation that are further barriers for the Roma population to obtain entitlement, especially for foreign and the most vulnerable national Roma.

4.2. Access to the healthcare system

According to NRIS, access to and use of the NHS and its services is key for improving the health conditions and the standards of living of the Roma population. The Operational Plan 2014-2016 of the NRIS "aims at an equitable, accessible and quality healthcare system, reorienting services to equity and removing barriers to access" (Ministry of Health, Social Services and Equality, 2013a). It is also proposed to remove the barriers for Roma to participate in prevention and health promotion programs. It also places special emphasis on removing barriers arising from cultural differences and the marginalized living conditions of some groups.

This section focuses on the following aspects regarding accessibility: (a) accessibility barriers for national and immigrant Roma; (b) consequences of these barriers for the Roma population, the health system and its providers; (c) policies and strategies implemented to eliminate these barriers; and (d) Roma health mediation.

4.2.1. Accessibility barriers

Several barriers that hinder the access of the Roma community to healthcare services arise in the contact between the Roma population and the NHS and its providers. These barriers have been intensified by the current socioeconomic situation (Fundación Secretariado Gitano, 2013; Laparra,

2007; López Catalán, 2012; Ministerio de Sanidad y Consumo & Fundación Secretariado Gitano, 2007). Many of the barriers presented here are due, first, to the lack of a healthcare system designed to reduce social inequalities (e.g., community work approach, integrating social and health services, no discrimination towards culturally diverse population), and secondly, to the Roma's living conditions (i.e., "living day by day", "survival", victims of racism, low educational level, etc.).

4.2.1.1. Barriers related to the scientific culture of the NHS

The NHS has been configured following a health science model characterized for looking the quickest solution to healthcare problems and for seeing patients as individuals unconnected to their culture (Trickett, 2011). Consequently, the current NHS implements a hospital-centered and ethnocentric model of assistance. As one of the providers interviewed for this report asserts:

"It is a system that does not cater for individual contexts (...). A patient may come here with a backache and painkillers are prescribed, but the fact that this person sleeps on the floor goes unnoticed. The context is the key; how patients live and where they live is also part of our concept of health (...). The system is made for the mainstream population and not for people in marginalised contexts."

(Mediator1)

This may lead providers to confuse equity and equality, mistakenly identifying people's right to healthcare with the accessibility of healthcare services:

"We don't treat anyone differently (...). They are all equal, so we don't have to implement positive discrimination with Roma families (...). What is it that they don't have access to? (...) They can come and visit patients, just like everyone else, but they can't come 20 at a time, but in twos and during visiting hours. It is a question of organisation. (...) They can come to the emergency service as many times as they like but, again, not 20 at a time. (...) They have a right to vaccinations, but they need to bring their children here to be vaccinated, just like everyone else. (...) They are given all the information they need (...) and they are given the informed consent forms for them to read, or for someone else to read it for them, or they are informed orally. (...). So, they enjoy the same accessibility as we or other ethnic groups do."

(Manager2)

However, access to healthcare services does not depend so much on the rights of an individual or a social group (equality), as it does on the adaptation of these services to the characteristics of this population, ensuring complete access to and use of these services (equity). At the same time, the system's ethnocentric outlook focuses on the dominant culture, and is not sensitive towards cultural differences and minority groups. In some cases, these differences may be even seen as cultural flaws, and the Roma community itself is made responsible for its health problems. All this results in a lack of specific protocols adapted to the characteristics and customs of the Roma population. One of the most recurrent examples is when hospitalised Roma patients are visited by relatives:

"If the patriarch, (...), the venerable elder, is ill, it is normal for different Roma communities to want to go and visit him; but there is a system, certain visiting hours and so forth, and that's when both cultures clash."

(Policymaker2)

Another unfortunate consequence of this NHS model are the cultural differences when defining the concept of health. The NHS acknowledges WHO definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (WHO, 1998). This concept implies the need to promote health, to gain control over it and to be able to improve it. At the same time, it also draws attention to the importance of reducing risk factors, preventing diseases, halting their advance and minimising their consequences. These ideas clash with those of the national and foreign Roma community—as well as other groups with low health culture—for whom health is simply the absence of disease. They understand disease in terms of symptoms, and their treatment in terms of eliminating these symptoms. This implies that they generally abandon treatment as soon as symptoms disappear:

"They only request healthcare assistance when they see symptoms."
(Healthcare provider2)

This means that Roma people only request healthcare services—mostly emergency services—when they are seriously ill or in acute disease processes that prevent them from going on with their lives (Mendez, 2007; Ministerio de Sanidad y Consumo & Fundación Secretariado Gitano, 2007):

"A woman suffering from toothache went to the emergency service three times (...). She was given antibiotics and an appointment was arranged to remove the tooth. Because the antibiotics got rid of the infection and therefore of the pain, she thought it unnecessary to go to the doctor's again and get the tooth removed."
(Social worker2)

This kind of ideas prevent Roma patients from anticipating health problems, planning actions and making medium- and long-term health-related decisions, something that makes prevention and health promotion rather difficult (Laparra, 2007):

"This is a community that (...) is not ready for prevention. They don't control pregnancies, and they don't do it because it is part of their way of thinking (...) in spite of the fact that they do have access to this kind of control."
(Manager3)

"If a woman goes into labour, they can even close down a whole market and get 200 people to accompany her, but they don't get a leukaemia test because it's not important for them."
(Healthcare provider2)

Situations like the described above may give rise to conflicts between the values of the Roma community (e.g., support and emotions in the face of illness and death) and the healthcare rules and regulations (e.g., visiting hours, number of visitors allowed, and so on). In this debate, some stakeholders wonder whether these conflicts arise from a lack of accessibility of healthcare services or from a lack of compliance with the rules by the Roma:

"Some of the difficulties that we encounter with the Spanish Roma population is precisely their lack of compliance with basic codes of conduct (...). There are complaints sometimes when there is a Roma patient in the Intensive Care Unit and about 50 relatives in the waiting room, with a little

stove and cooking a stew (...). I understand these are their customs, but they are irreconcilable with those of the mainstream population, aren't they? So, conflicts arise, but these are not related to assistance or equity."
(Manager3)

Very often, this cultural gap is rooted in the system's blindness of the Roma culture, something that is accentuated by the fact that very few health providers–and prospective providers—have received adequate training in managing diversity:

"Our NHS is not ready professionally to deal with exclusion, and it does not know how to manage diversity because neither at university nor anywhere else are providers trained to work in conflict areas."
(Mediator1)

This unawareness encourages prejudiced and stereotyped visions among providers, who sometimes see the Roma community as a self-marginalised people, and consequently leads them to use strategies that result in communication problems.

The above shows that the Roma community has cultural codes that are reflected in their customs, values and practices. An example of this is when Roma people - even those in relatively better socio-economic situations - consider disease and other health problems as taboos, sometimes even denying they exist. This may be one of the reasons why many Roma women do not go to the gynaecologist:

"Whether in marginalised contexts or not, the truth is that Roma women don't go to the gynaecologist; it is a taboo subject for them."
(Mediator1*)*

It may also be one of the reasons why they do not report gender violence:

"In order to set up a protection protocol for gender violence, the woman or the family need to report to another Roma and to a non-Roma institution. This may lead to a conflict between Roma families and this is the reason why, except in extreme cases, they don't generally report it."
(Policymaker1)

4.2.1.2. Barriers derived from miscommunication and misinformation

The NHS has rigorous protocols of access that make use of *"a whole new language and an internal organisation that you need to learn to understand the system."* **(Social worker4).** For example, administrative and bureaucratic procedures are the first barriers that Roma people encounter when attempting to access the system or when following stipulated procedures. Basic knowledge and communicative skills that are beyond the users' own resources are required to navigate the system. In the case of foreign Roma, they do not even know the language. It is for this reason that some users feel immediately excluded from it:

"Is the system in favour of people or in favour of bureaucracy? (...) There are several barriers if one wants to understand how the system works."
(Social worker4)

"Regarding Eastern European Roma, the first obstacle is always the language (...). We have serious difficulties in communicating with them."
(Manager3)

Regrettably, the NHS offers scarce resources to reduce these barriers. For example, the information available is mainly produced in written form (e.g., brochures, posters and websites, among others), and it does not reach the national and foreign Roma population because it is not adapted to their culture, language, or education level. Translation services—either face-to-face or online—are not generally available in Romani. Also, there are very few intercultural mediators immediately available for healthcare providers and users:

"There is not a mediator in the clinic that can become a reference person for Roma patients (...). As it happens, they generally get the information from someone who has nothing to do with healthcare and has no responsibility in the centre (...). It is not compulsory for health centres to offer this kind of service, a person who can explain everything to these people"
(Policymaker2)

On the other hand, access to the system and, consequently, to healthcare services and resources, depends on the information that both users and providers have about users' rights:

"People who don't have information about their rights cannot claim them."
(Social worker1)

As a general rule, Roma patients are not aware of their healthcare rights or the way in which the NHS works. However, approximately 91% of national Roma used public health services in 2011, compared with 69% of foreign Roma, 75% of Moroccans and only 50% of Indian-Pakistani immigrants. This data seems to suggest that national Roma are highly aware of their rights (Laparra et al., 2012). In contrast, foreign Roma's knowledge of the NHS and their rights is scant, either because they reproduce the patterns of access and use in their countries of origin, or because the information they have is inadequate, since they get it from relatives or friends (Slavkova, 2010):

"Foreign Roma (...) are not integrated in our health culture, they are not aware of the services and resources to which they have right, because in most of the countries where they are from, mainly Central Europe, there are difficulties regarding access, so they think it's the same here."
(Manager5)

Together with this lack of awareness on the part of users, providers are also generally unaware of users' rights. The providers who have been interviewed for this report maintain that they have encountered this barrier when this should be part of the basic knowledge and training of all providers, especially of those in the administration who manage access. This lack of awareness, together with the high level of staff turnover, means that some social workers from the healthcare centre or Civil Society Organizations (CSO) have to accompany users to healthcare centres in order to 're-educate' these providers and guarantee access for Roma users:

"In many centres, they say 'no' straightaway to Roma users (...): minors, pregnant women, emergency cases... But then you accompany them and you tell the professional what the law says,

that they have to issue a Health Card and that they have to assist them, and that's when they do it."
(Social worker2)

"The access depends on the person who is at the entrance of the healthcare centre (…) once we accompanied a pregnant woman and the administrative asked us "how do we know if she is pregnant?" first, she has to pay the bill and then we will know whether she is pregnant or not". Well, that is not a misunderstanding of the Law..."
(Social worker3)

"Theoretically, they have to assist them even without a Health Card, but (...) sometimes (...) they make them pay first, telling them that they can claim their money back when they have their Health Card. If we go with them, they are assisted straightaway because we ask them to (...). It all depends on the centre and the person at the reception desk."
(Social worker2)

This misinformation results in a deficient application of the rights that ensure access to the NHS for some national and foreign Roma. The providers interviewed maintain that they do not deny medical assistance to anyone even if they are not entitled. In the same line, the Roma Decade Civil Society Monitoring Report 2012 (Laparra et al., 2012) states "the percentage of Roma people that requested medical assistance and did not receive it is similar to that of the general population" which is among the lowest percentages in Europe. The current legislation (see section Entitlement) guarantees access to the NHS and its services for pregnant women, children under 18, and emergency cases. Nevertheless, there are situations in which the lack of information on the law prevents its right application. For example, in some AACC there are inconsistencies and unresolved questions about how to apply the law when dealing with population that is not registered in the census (Fundación Secretariado Gitano, 2012):

"Adults not registered in the census may not access the system (...) unless it is an emergency; but it is the person at the front desk who decides what an emergency is and what is not."
(Social worker1)

Pregnant women are sometimes only assisted when they have pregnancy-related problems but not in other health situations:

"Theoretically, the law says that they have to be offered assistance (...). In the past, there used to be monitoring during pregnancy and the forty-day period after childbirth, but the situation is worse now. (...) For example, a pregnant woman is not offered assistance if she suffers from gastroenteritis or dental problems, all of which may be caused by pregnancy, because the law is interpreted as concerning strictly gynaecological problems."
(Social worker4)

In the case of children, the law guarantees that they receive medical assistance under the same conditions as any other Spanish citizen. However, in these cases (i.e., pregnant women and children), the NHS does not cover specialised assistance (e.g., rehabilitation, ophthalmology, otolaryngology, etc.) which is only provided via emergency services:

"This means that if a child suffers from otitis, she is given everything she needs, antibiotics and so on. However, if she has a perforated eardrum and she has to be seen by a specialist, she can't."
(Social worker3)

4.2.1.3. Barriers derived from exclusion and marginalisation

Historically, the Roma community has suffered discrimination and social exclusion experiences that have been assumed and perpetuated generation after generation. This has given rise to situations of marginalisation and segregation that affect the relations between this community and healthcare services. In the first place, the Roma community does not identify with, no feel represented by, the NHS. Moreover, many Roma distrust and are afraid of healthcare services (Slavkova, 2010):

"They are really afraid (...) afraid that their children might be taken away if Social Services believes there is parental negligence (...). So, they think of it as a form of surveillance, rather than as a form of help."
(Mediator2)

Similarly, some healthcare providers are often reluctant to work with the Roma community due to prejudices and stereotypes, thus resulting in racist and discriminatory health practices towards the Roma. Secondly, the system disregards the geographical exclusion of its potential users, something that perpetuates the segregation of the most vulnerable sectors of the Roma community. In this way, the geographical location of marginal areas and settlements, together with bad transport connections between these areas with healthcare centres, or the fact that there are no health centres in these areas, create further barriers, preventing these people from accessing the NHS and its services. In fact, **these areas and settlements are very rarely the sites of health visits, health prevention programmes or programmes to engage users who have never accessed the system**. Some studies (Laparra, 2007; 2011) have found a direct relation between housing difficulties and lack of access to healthcare services, and also between the need to access specialised assistance and difficulty in reaching these services. Moreover, the mobility of the Roma population further accentuates these and other barriers: for example, traveller patients are difficult to monitor because every time they move they need to be assigned with new doctors and new medical records are open.

4.2.2. Consequences of accessibility barriers

The main consequence derived from these barriers and the Roma community's health condition is the fact that national and foreign Roma have developed **non-normative patterns of access to and use of healthcare services** (Fundación Secretariado Gitano, 2012; La Parra, 2009; Laparra, 2011; Mendez, 2007):

"Primarily, what you see is that they don't keep their appointments, that they use the emergency service a lot and that they don't generally continue treatments"
(Mediator1)

As a general rule, Roma people make deficient use of healthcare services because they do not stick to established times, because they find it difficult to continue treatments or to keep their appointments, because they do not go for check-ups, or because they do not follow prevention programmes. Also, this population's access to services that are not covered by the NHS—preventive

services such as dental care or eye care—is much lower than that of the general population (Laparra, 2007; Ministerio de Sanidad y Consumo & Fundación Secretariado Gitano, 2007). However, this assertion should be qualified: Roma children use healthcare services more often than adults, although less than the general population; and also Roma children make use of hospitalisation and emergency services more often than of primary care and healthy child programmes (Ferrer, 2003; Sánchez-Serrano et al., 2002).

All this leads to increase reliance on emergency services. This overuse has been discussed by some stakeholders, who contend that integrated Roma make rational use of the NHS, the difference with the mainstream population being minimal:

"There was time when adults were issued Health Cards if they applied for them. Even back then, they did not use the service more often than they do now, because, in any case, they don't come here unless they are really, really ill."
(Social worker4)

Furthermore, it is stated that the increase in healthcare costs is not exclusively due to service overuse on the part of Roma patients, but rather to the fact that their access has been limited to emergency services:

"They don't incur expenses of public money such as health centres or nursing homes. The elderly are taken care of at home, there is a big family network to tend ill people at home, where care is normally done. If we really did the numbers, we would realise that Roma people spend much less money than other communities."
(Manager4)

"Current policies promote a very bad use of emergency services, which are also more expensive than primary care."
(Social worker1)

Although Roma people generally do use the NHS, a small 'upper-class' of Roma resorts to private healthcare, which provides them with the immediacy, familiarity, and empathy they expect from healthcare service (Cabedo García et al., 2000; Laparra, 2007):

"They want to spend their money on that kind of service, but they don't receive preventive information there."
(Healthcare provider2)

4.2.3. Policies to suppress accessibility barriers

In order to ensure that everybody can access the NHS and its services, regional governments, CSOs, healthcare organisations, and providers implement a series of actions and strategies to prevent the exclusion of Roma people from the system. Together with the guidelines elaborated by the Catalonian and Andalusian governments (see Entitlement), which secure access for those excluded by the RDL 16/2012, there are other national and regional policies intended to eliminate these accessibility barriers. For example, at a national level, the Action Plan for the Development of the Romani population (2010-2012) attempted to improve the use of healthcare services, reducing accessibility barriers and improving access to certain specialised services and tests, such as

ophthalmology and otolaryngology. At a regional level, the Integrated Plan for the Roma Community of Andalusia (1996) intended to expand medical coverage and to guarantee full accessibility by improving the mechanisms of guidance and access, and by promoting Roma patient's knowledge and use of the system.

4.2.4. Strategies implemented to overcome accessibility barriers

From an organisational viewpoint, the NHS and its regional services have **a series of mechanisms and strategies in order to facilitate access for the Roma community**. For example, there are some specific health programmes that offer assistance to people suffering from tuberculosis or drug abuse, even if they are not registered in the census, as well as committees set up to discuss important health issues and cases of people who are not covered by the system:

"In this committee we have dealt with 70 to 80 cases, 90 per cent of which have been approved."
(Policymaker3)

Also, both CatSalut and SAS have electronic information points (i.e., *Sanitat Respon* and *Salud Responde*) and websites with information concerning healthcare access.

However, most of the efforts made to remove accessibility barriers are within the scope of individual responsibility of providers, thus implying a high component of improvisation, voluntarism, ad hoc approaches, etc. which may involve work exhaustion and burn-out. For instance, healthcare providers may accompany Roma patients to the front desk and demand the administration staff to include them in the system even if they are not entitled to health and hence not registered in it:

"In order to treat these people, they have to be in the system. Administrative officers may create a conditional medical record (...). There is always a way to do it."
(Healthcare provider2)

Social workers also play an important role in Primary Healthcare Centres (PHC) - for example, by taking part in community interventions and commissions with several other agents in the area (Box 4):

"We run a community project in order to include families in the system (...). Mediators who know them call me and we meet (...). I accompany them to the reception desk, we do all the paperwork, I clarify things for them."
(Social worker4)

Box 4: Community intervention within a Basic Healthcare Area

The Santa Rosa Basic Healthcare Area (Santa Coloma de Gramenet, Barcelona) is the responsible for promoting and guaranteeing healthcare attention to the whole population located in the territory (i.e. Sta. Rosa, Raval and Safareigs de Sta. Coloma de Gramenet). In order to do so, the Basic Healthcare Area focus on the community dimension of intervention, detection and health prevention. In this area, there are Romanian Roma disconnected from the PHC Sta. Rosa, in negligence and health risk that only makes use of emergency services through the hospital. Within this group, the Basic Healthcare Area detected in 2006 minors without register in the city council or school, without healthcare card, without vaccinations, and pregnant minors without gynaecological

monitoring. Facing these challenges, the social workers of this healthcare area, contact the different competent authorities (e.g. NGOs, social services, area of education of the municipality, etc.) to raise awareness about this situation, this creating a commission for the community work in the area.

Regarding CSOs, the work of mediators and social workers is key in guaranteeing healthcare access for the national and foreign Roma population. Along this line, alternative forms of access have been created: for example, by elaborating non-official censuses, which allow providers to engage, identify and monitor users in situation of exclusion. Also social workers may certify that a given family or individual is in a situation of exclusion so they can be granted access; or if a family do not have a fixed address, they may be registered in the census under the address of a CSO (López Catalán, 2012):

"They manage (...), the social worker in the centre may make a report so that the child that is not registered in the census may have a Health Card in the same conditions as any other child."
(Social worker2)

"It is difficult if the person is not registered in the census (...). However, I know of an association in Barcelona whose address can be used if the patient doesn't have a fixed address."
(Manager3)

Health mediation programs are also a very important strategy, as they seek to raise awareness, to empower users and to enhance their autonomy by promoting knowledge about their rights, about how to do paperwork, how to make appointments, and so on:

"The idea is (...) that people must know their rights, they must know that they can go to the doctor's if they are sick, but also that they have to go (...) that this is something that affects all of us (...). I remember the case of a foreign Roma with tuberculosis. We had to convince him to go to the doctor's in order to prevent all of us from getting it."
(Social worker1)

"It is already difficult to get them [Roma population] to go and do prevention and monitoring programmes, things that they don't do in their own countries. Imagine if we send them to the PHC here and they are denied access (...). What we want is the guarantee that they can go there on their own and that the law is complied with."
(Social worker3)

Nevertheless, these alternative forms must be constantly updated or finetuned in order to continue to guarantee access to both primary care and specialised services. Moreover, these strategies and programmes cannot completely eliminate accessibility barriers, leading social workers and users alike to exhaustion or burnout, generating dependence on social services and the collapse of the most sensitive centres.

Yet another way to access the NHS is via other systems, such as schools and workplaces. As shown in the case study presented in the section on achieving and sustaining change, participation in job placement programmes and discussion groups did not only allow Roma women participants to be

trained in occupational health, but it also favoured the creation of alternative forms of access to healthcare services, especially regarding healthy habits, prevention, and promotion programmes.

4.2.5. Roma health mediation

An urgent task to improve Roma health equity is to bridge the gap between minority cultural groups suffering vulnerability and the NHS. Health mediation is addressing these challenges in Spain through public institutions participating in policymaking, health centres, and programmes and activities implemented and funded by social institutions (e.g., La Caixa). However, the most successful health mediation actions, programmes, and activities are those implemented by CSOs). These programs often have a localized character, they are organized through a small number of workers or mediators in these associations, and the degree of institutionalization and integration in the NHS is rather limited.

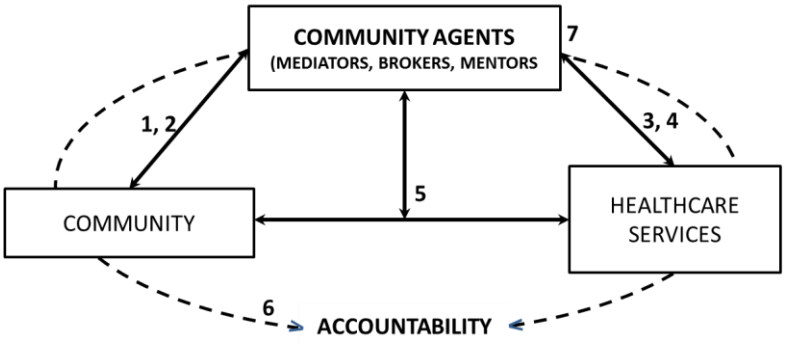
Health mediators are both community liaison officers and cultural brokers. They must be acknowledged by the community, share its values, beliefs and practices, and become community mobilisers. They also have to be proficient in medical communication, act as interpreters for the community and promote channels of communication among all social levels. Finally, they must have in-depth knowledge of the community's needs and strengths and be expert navigators in healthcare organisations and systems (Family Voices, 2009):

"They are not translators, they are not doctors, they are not nurses, but they have to be all these things at once."
(Mediator2)

Furthermore, health mediators work at different levels: (a) community (e.g., families, individuals, and so on); (b) public services (e.g., schools, hospitals, health centres and so forth); and (c) policymaking institutions (e.g., regional and local governments).

The health mediation process seeks to achieve two main goals: in the short term, it seeks to build bridges between the community and healthcare services; in the long term, it aims to bring the community closer to healthcare services. This process consists of seven stages (see Figure 4):

Figure 4: Health mediation process



1. Being aware of community needs through their participation in the community
2. Working with the community to improve their health at different levels (e.g. family, children, workplaces)
3. Navigating and acquiring a status among healthcare staff
4. Working with healthcare systems to improve community´s health
5. Making culturally sensitive healthcare services and increasing community health literacy
6. Assessing the impact of health mediation processes in terms of quality of healthcare and health status
7. Training health mediators

In the first place, in order to *be aware of community needs through the participation of mediators in the community* (1), most CSOs develop participant observation, asking different members of the community, listening to their requests, doing photo voice activities and answering the demands of services to develop specific protocols (e.g., the voluntary interruption of pregnancy programme by Unión Romaní). Other examples are the visits paid by Unión Romaní to shantytowns in order to locate unvaccinated children, carry out first aid workshops, and elaborate a contextual census of excluded people. In the same line, members of FAKALI visit schools to contact parents and know about their children's needs, while VINCLE has created a network to study the condition of foreign Roma[15].

Secondly, in order to *work with the community to improve their health at different levels* (2), organisations like FAKALI and Unión Romaní promote community revitalisation and autonomy. For example, because they do not intend to be permanent mediators, they encourage Roma users to become mediators —and role models—for their families. Also, Unión Romaní develops programmes and protocols to teach how to navigate in the NHS, how to get children vaccinated, to do paperwork, to buy medicines and shop healthy, and to raise awareness of patients' rights and responsibilities in healthcare. FAGIC, FAKALI, and Fundación Secretariado Gitano also develop training programmes on healthy habits, reproductive health, nutrition, violence against women, HIV prevention, addictions, and so on. Most organisations accompany families to health centres to ensure access and to facilitate communication with providers. VINCLE and Unión Romaní also provide information and do paperwork for Roma users.

In the third place, to *navigate and gain acknowledgement among healthcare staff* (3), FAKALI and FAGIC organise conferences and meetings in hospitals and PHC where mediators disseminate the results of their work and build critical awareness among staff. Unión Romaní establishes agreements with health centres to help healthcare providers and to get them involved in the association. At the same time, FAKALI attends meetings with regional and national political organisations to secure the role of health mediators as new healthcare providers. Also, they collaborate with social workers in health centres for planning interventions. Finally, most organisations use communication platforms to publicise their work (e.g., websites, reports and papers, among others).

In addition, *working with healthcare systems to improve the community´s health* (4) is done by Unión Romaní - for example, by offering mediation and translation services to healthcare centres in specific situations. FAKALI and FAGIC train health providers in law, cultural competence and knowledge of the Roma population in hospitals and health centres. FAKALI also organises training courses for healthcare students. Finally, some organisations have developed guidelines such as the Handbook for Action in the Area of Health Services with the Roma Community (Fundación Secretariado Gitano, 2006).

Furthermore, *to make culturally sensitive healthcare services and to increase community health literacy* (5), FAKALI and FAGIC create spaces for dialogue, facilitating channels of communication, redefining problems and redistributing power and resources. For example, they have created health coalitions where healthcare providers and the Roma community get together, creating

[15] http://www.romest.cat

local/regional/national networks among multiple stakeholders (e.g., Roma organisations, user representatives and policymakers):

"We are going to change the way we work, at least we are going to try, we are going to create a health committee, we are going to invite all Roma women to come and participate."
(Mediator1)

Regarding the *assessment of the impact of health mediation processes in terms of quality of healthcare and health status* (6), formal methods using quantitative and qualitative indicators are not frequently used in health mediation in Spanish organisations. Rather, assessment is generally carried out in a more contextual, participatory, and observational way. For example, through familiarisation with and commitment to the community, its characteristics and needs; also, by being acknowledged by the community and being part of it; finally, by ensuring quality in the mediation process, by facing and adapting to changes, and by being sustainable.

Therefore, health mediator training should cover: knowledge about the NHS (e.g., navigation); medical knowledge (e.g., nutrition, STD, smoking, maternal and child health); legal knowledge on health issues; social skills—especially empathy and leadership; cultural competence; and knowledge of the Roma community and their health. Some examples of these courses are Catalonia´s Migration and Intercultural Mediation Health Plan 2008-2012[16] or the Training Course for Roma Mediators "ROMED"[17] (MSPSI, CoE and FSG).

Box 5: Highlights of Access to healthcare system

The NRIS establishes the accessibility of healthcare services as one of the strategic lines of action to improve Roma health. National and foreign Roma have developed non-normative patterns of access to and use of healthcare services due to the following challenges and barriers:

- The Roma fear and distrust the systems and its providers due to their historical marginalization and persecution.
- The NHS disregards the geographical location of marginal areas and settlements where many Roma live. Plus the bad transport connections and the mobility of the Roma population create further barriers to access the NHS.
- The NHS ignores the Roma culture (e.g., few providers are trained in managing diversity, lack of adaptation of healthcare services and protocols to the Roma population, and deficient channels of communication).
- The lack of ethnic-related information prevents knowing the exact number of Roma people, which further their invisibility in plans and strategies not developed in accordance with their needs.

However, there are some strategies that have been developed in order to ease these accessibility challenges:

- National and regional policies have been created to ensure access (e.g., the Instructions of Andalusia and Catalonia, the Action Plan for the Development of the Romani population 2010-2012, or the Plan for the Roma Community of Andalusia 1996)
- Healthcare centres have developed mechanisms and strategies in order to facilitate access for the Roma community (e.g., specific health programmes, committees, information

[16] https://obrasocial.lacaixa.es/deployedfiles/obrasocial/Estaticos/pdf/Inmigracion/Mediacio_intercultural_es.pdf
[17] ROMED https://www.gitanos.org/actualidad/archivo/60869.html

points).

- Providers from healthcare centres and CSOs make a great effort to reduce accessibility barriers (e.g., by taking part in community interventions and commissions with several other agents in the area, accompany programs, developing alternative ways to access, etc.)
- Health mediation processes carried out by CSOs are the most effective way to enhance the accessibility of Roma population while improving the health of this community. The objectives are to build bridges between the community and healthcare services, as well as to bring the community closer to healthcare services.

4.3. Responsiveness of healthcare services

The Operational Plan of the NRIS (2014-2016) (Ministry of Health, Social Services and Equality, 2013a) aims to reorient health services towards equity, both in the areas of health promotion and disease prevention and healthcare, with special emphasis on groups that accumulate more risk such as children and women. The activities proposed are: provide training to improve equity in healthcare services, improve cultural sensitivity of resources, support and promote training actions for diversity and cultural competence among health providers; and train CSOs for effective mediation between communities and services.
In this section these aspects are evaluated following these subsections: (1) prioritized health inequities in the NRIS (Plan Operativo, 2014-2016); (2) policies for more responsive NHS for the Roma population, (3) adaptation strategies and service providers; and (4) good practices addressing Roma specific health needs.

4.3.1. Health inequities identified in the NRIS

The NRIS health objectives are based on the results obtained in the only reference comparative study done in Spain. This comparative study primarily draws on the national surveys carried out with Roma and non-Roma population in 2006 (La Parra, 2009) and, to a lesser extent, on the Health and the Roma Community survey (Ministerio de Sanidad y Cosumo & Fundación Secretariado Gitano, 2007). The study compares the differences between national Roma and non-Roma population regarding certain types of diseases and lifestyles. As a result, the NRIS focuses on the health inequities of national Roma, disregarding the increasing number of Roma coming from Romania and Bulgaria. This may be explained by the lack of information about foreign Roma and their health inequalities and social determinants in Spain:

"We have to know exactly what to tackle. So far, we don't have that information, so we are acting blindly."
(Manager1)

Although the people interviewed for this report acknowledge the importance of the objectives set by the NRIS, they also draw attention to the limitations of its exclusively biomedical perspective, disregarding the social determinants that surrounded these communities, specially the foreign Roma:

"Regarding health in the NRIS, I've been hearing the same things for years. Look, in three years, we've gone this far and, in four years, we've achieved this. This is all consolidated now, so why should we repeat the same objectives over and over again?" **(Manager5)**

"An unfavourable setting such as a settlement (...) raises a child's chances of getting sick or of having an accident. If the father does not work (...), if he has a low education level and other more serious problems, (...) he is not going to be concerned with healthy eating."
(Social worker1)

"Why are there 20 people living in a flat? Because people don't generally rent out flats to them. It's not that they want to live in these conditions. (...) Here we meet smelly children, we ask them and it turns out they don't have running water (...). Housing is also health. If they suffer from scabies, how do we treat them at home? (...) Treatments are very specific in this case: to throw everything out, to wash everything at 60 degrees, lotions, no contact (...). If there are 20 people in a flat, what can you do?"
(Social Worker4)

The interviewees also explain that the **objectives are not interconnected and integrated within other existing strategic elements of the NHS** (e.g., regional health plans, national legislation, national strategies for cancer, cardiovascular diseases, etc.), in spite of the fact that the NRIS proposes certain cross-sectoral lines of action (e.g., administrative participation and collaboration, accessibility, and use and efficiency of healthcare services).

4.3.2. Policies to make healthcare services more responsive

In the elaboration of some of the plans and policies implemented in Spain, the need to create services, procedures, and resources that are responsive to the Roma population has been considered by different sectors. At national level, the focus has been placed on the **training of providers, the implementation of integrated and sensitive practices, the elaboration of reports and reference guides about the health of the Roma community, and the adaptation of informative, preventive and promotional campaigns** (National Action Plan on Social Inclusion in Spain, 2008-2010; Action Plan for the Development of the Romani population, 2010-2012; National Strategy for Health Equity for the Roma Population, 2003). At regional level, Catalonia and Andalusia follow the same guidelines, stressing the training of providers and the adaptation of resources, services and programmes to this population. As an innovative measure, they seek to appoint providers in health centres and regional health agents of Roma origin, and to expand awareness of the Roma population within the NHS (e.g., providing meeting spaces in hospitals) (Immigration Master Plan for Health in Catalonia, 2006; Integrated Plan for the Roma Community of Andalusia, 1996; I and II Integrated Plan for the Roma People in Catalonia, 2005-2008/2009-2013).

Despite all previous attempts to make a more culturally sensitive NHS, there is no integration of all the above contents in the academic curriculum of health studies at Spanish universities (e.g., medical and nursing degrees) or in permanent training programs of the different regional Ministries of Health. The few existing exceptions are elective courses or courses outside the official curriculum (e.g., special courses, degrees of expertise), which are more focused on immigrant population rather than the Roma community.

4.3.3. Adaptation strategies of healthcare services and providers

For the most part, healthcare services do not have protocols specifically adapted to the Roma community (Cabedo et al., 2000):

"Lack of access to preventive programmes is mainly due to policies not being adapted to the circumstances of this community. Healthcare providers can't materially promote these programmes and informative brochures are written in a language that patients don't understand."
(Manager5)

Nevertheless, in areas with a high Roma population density, healthcare centres and providers have adapted these general protocols and practices to the circumstances and needs of the Roma users. Most of these adjustments are not official although all providers implement them. This involves, at the very least, a great degree of coordination and collaboration among staff:

"One of the principles that we apply is that we immediately vaccinate children that have not been vaccinated. (...) The priority is for the child to be protected."
(Social worker4)

The staff needs to be proactive and constantly vigilant, especially regarding the locating and monitoring of patients (e.g., system alerts, telephone calls, contact with regional services and agents, home visits outside working hours). All this may lead to occupational *burnout* or emotional exhaustion, in spite of the fact that these actions are also seen by providers as *"investments to improve the health of the Roma"* **(Social worker4).**

Some of these adjustments have to do with adapting health practices to the Roma religious beliefs which foster spiritual health and strengthen support networks. However, these must also be compatible with medical treatments and not interfere with the decisions and guidelines of practitioners:

"In the case of a child, we had to intervene because the parents refused medical treatment arguing that God would heal her."
(Manager4)

In case of death, in order to make medical procedures and religious beliefs more compatible, some hospitals in Catalonia have implemented the use of a 'mourning assistant:'

"Roma people deal with death in a way that we don't understand; and the way we manipulate and transport bodies is unacceptable for them."
(Policymaker2)

Another adjustment is the possibility of choosing a male or female doctor, especially when dealing with women's health problems. This sometimes generates contradictions:

"If the only two gynaecologists in one centre are male, we tend not to refer the patient to a different centre. Adaptation is a mutual process."
(Policymaker3)

Also, and due to the current economic crisis, many providers have adapted their practices to their patients' economic situation, for example, by prescribing cheaper medicines or by resorting to charity resources and drug banks outside the system. These adaptations are easier to implement in PHC than in specialised centres and hospitals:

"Here [at the PHC centre], we are quite aware of all this, but specialists' prescriptions can be really expensive for a Roma patient"
(Healthcare provider1)

Notwithstanding, Roma patients consider that the assistance they receive from the NHS is deficient. What they expect from a quality healthcare service is to offer longer consultations in a more empathic and intimate atmosphere. These expectations clash with the reality they face when they seek assistance and this is the reason why they stop going to the doctor's appointment:

"The language used by practitioners is rather technical (...). This makes Roma patients feel uneasy (...). It is also important for them to be with the doctor for a little bit longer, to have the chance to speak at ease. Nowadays five minutes is just not enough for them."
(Mediator2)

"Medical jargon is difficult to understand for a person with no academic qualifications (...). They feel that they can't communicate with doctors, that doctors can't teach them anything (...) and so they either confront the situation the best way they can or they stop using the service and only resort to it when they are already very ill."
(Mediator1)

That is why changes in the communication between patient and doctor are also done in order to offer high quality care (e.g., informative and visual collages). The most responsive staff is aware of the communicative and interpersonal characteristics of the Roma population when organising workshops and talks in health centres and schools:

"They don't really like doing things in groups, especially things related to maternal education; they are afraid or ashamed, I'm not sure." **(Healthcare provider2)**

At the same time, healthcare providers have to follow bureaucratic protocols that contemplate a series of objectives that are neither adapted to the characteristics of Roma population nor to the circumstances in which the service is provided:

"There is pressure because the objectives set for doctors in all the centres, including this one, are linked to economic incentives, and these are not adapted. We are given economic incentives according to certain recommendations, to prescription prices, the number of prescriptions by active ingredient, or the number of referrals (...). Here, for example, when you refer patients and the appointment is in six months, they end up missing it. Then they come to see you again and you refer them again, four of five times if necessary, and they keep missing the appointment. Also, because we know these people don't have a chance to go the dentist, we tend to prescribe antibiotics a lot. We are penalised for all this."
(Healthcare provider1)

"Doctors here are supposed to have a smaller number of patients than in other areas in Seville (...). The difference is that this is the only health centre in the area. In Los Remedios, in Huerta del Rey, out of 2000 patients per doctor, only 500 actually demand public health services. The rest of them either have private healthcare or don't go to the doctor's for every single thing."
(Healthcare provider1)

Box 6: Good practices addressing specific Roma health needs

One of the measures enlisted in the NRIS to improve the responsiveness of the NHS is to create **new services and programmes that address the specific needs of the Roma population**. In this way, the NRIS promotes the effective integration of equity through the translation and implementation of the *Methodological Guide to Integrate Equity within Strategies: Health Programs and Activities (Guía Metodológica para integrar la Equidad en las Estrategias: Programas y Actividades de Salud;* Ministry of Health, Social Services and Equality, 2012c).

"El deporte traspasa fronteras"[1] Initiative promoted by the CSO Fakali and sponsored by Decathlon and Lot of Colors which aim to promote health through sport in Roma women, female teenagers and girls at risk of exclusion. Other transversal objectives are to promote the values of sport (e.g., effort, perseverance, teamwork...), improve self-esteem, nutrition and hygiene, as well as improve coexistence and rehabilitation of the neighbourhood. This program took place in Sevilla, in the marginal neighbourhood "Las 3000 viviendas" located in Polígono Sur during 2014, in which different sports and physical activities were organized weekly (e.g. cycling, football, zumba, aerobic, skating, field excursions, etc.).

- **"Sol i Escola"** is a community intervention project for Roma minors as a result of the commission created by the Santa Rosa Basic Healthcare Area (Box 4) and which took place from July to September, 2007. Among the general objectives there are to detect and prevent risky situations for Roma minors, to work hygienic habits with them, to know Roma families living in the area and work with them schooling for their children. More specifically, in health, the objectives are to tackle every dimension of health within the families' difficult situations, to prevent risks for public healht, to incoporate minors to the NHS as well as to the healthy children program, to reduce the use of emergency services, and to guarantee the continuity of medical treatments. Among the services and activities, the program offered shower and launderette facilities, as well as clothes and equipment for school.
- The project implemented by **La Mina PHC centre** (Barcelona), aimed to improve the mental health of Roma mothers. These mothers attended the community centre with their babies and, through collaboration and daily activities, they were trained in positive parenting. Besides, their babies were taken care of so they could have time for themselves. This project also included talks about topics chosen by the mothers, and experts from the area were invited to take part. This was a way to empower communities by stressing the work of their providers and by increasing their involvement in the community.

4.3.4. Case study: The sexual and reproductive health program for national Roma women in the Poligono Sur neighbourhood of Sevilla

4.3.4.1. Background

Polígono Sur in Seville, the capital city of Southern Spain, is an area of about 145 hectares made up of six districts in need of economic and social development. Population is estimated at 50,000 inhabitants. Over two thirds of the inhabitants are illiterate and only 7.3% of the population hold professional or academic qualifications. The current working plan in the area is the "Plan Integral del Polígono Sur de Sevilla" (2006-2014), a programme focused on four types of actions: (1) Urbanism and coexistence; (2) Social and professional integration and economic activity promotion; (3) Community welfare; and (4) Socio-educational and family mediation.

In the area, there are districts with poor health and sanitation levels. Specifically, there are faecally contaminated waters on the streets, damp houses, rats, cockroaches, insects, buildings with no water supply, and the like. Polígono Sur doubles the number of cases of health issues of the rest of the city. The male population mostly suffers from AIDS, chronic obstructive pulmonary disease, stomach and lung cancer, and respiratory and infectious diseases. In the case of women, they mainly suffer from infectious diseases, breast cancer and respiratory and digestive diseases. Regarding sexual health, teenage pregnancy represents 17% of the total population and 35.7% of the cases are unintended. With regard to voluntary interruption of pregnancy (VIP), 64% of the women had never visited a family planning centre. In most cases, the reasons are economic (55.35%) or not wanting to do it (35.71%) (Comisionado para el Polígono Sur, 2006).

There are two PHC in the area - "Polígono Sur" and "Las Letanías." There is also a drug abuse treatment centre. For specialised services or mental health problems, patients must go to a hospital outside the area, Hospital Virgen del Rocío.

In the above referenced context of social vulnerability, this study aims to assess the achievements and good practice of healthcare providers in the family planning programme addressed to the Roma community in the Polígono Sur PHC centre. In particular, this analysis focuses on the elements and procedures that explain the success of this programme among the Roma population, offering an example of good practice that can be transferred to other centres in similar conditions. The centre has been running since 1989. It is open from 8am to 8pm Monday to Friday, providing primary care and emergency services.

4.3.4.2. Research questions

a) Which indicators define the success of the family planning programme in the Polígono Sur PHC centre?
b) What are the challenges regarding the Roma population in terms of family planning?
c) What skills and strategies have health practitioners developed in order to efficiently tackle these challenges?
d) What elements are considered challenges that still need to be faced?

4.3.4.3. Research process

Information and data collection was done by three researchers and two collaborators (members of the Coalition for the Study of Health, Power and Diversity, CESPYD) from the Faculty of Psychology at Universidad de Sevilla. In order to obtain evidence necessary to answer the research questions, the following qualitative methods of data collection were used:

- *Data collection*: Analysis of written documents or registers produced by the people involved in the family planning project.
- *Participant observation*: Description of what researchers have observed during their time at the PHC, in interviews and in the focus group.
- *Interviews:* As a result of the communicative interaction between researchers and participants, individual narratives of the people involved in the family planning programme were obtained. Specifically, there were in-depth interviews with (a) the midwife, (b) one of the family doctors, and (c) five users of the family planning service of Roma origin.
- *Focus group:* Group interview addressed to the practitioners in charge of the family planning programme in the PHC centre (i.e., two family doctors, two nurses, and two nursing

assistants). The information obtained came from interactive dialogue and shared knowledge.

During the process of data collection, extreme care was taken to ensure that the information collected was representative of the community by guaranteeing the participation of different user profiles. This required researchers to absorb the culture of the people involved in the study (i.e., to understand their point of view, their values, jargon, ways of thinking, and the like). Also, informed consent was obtained from all interviewees to record and use the collected data, ensuring both their anonymity and the use of the information for research purposes only.

All the providers in charge of the family planning programme who were interviewed were women with two to twenty years of experience in the PHC. Their real names have been changed in order to maintain their anonymity.

Some of the open questions used in the interviews with the users of the family planning programme were: When did you start attending the programme? How often do you attend? How will you rate the way you were treated in the programme? How do you consider communication with the practitioners? Have you faced any problems in this programme? Will you recommend the programme? Some of the questions addressed to the providers in the centre were: When, how, and why was the programme created? Which are the indicators of success of the programme? Why do you think the programme is successful? What are your motivations for working in such adverse circumstances? Which competences contributed to the programme's success?

All the interviews and the information provided were transcribed and analysed. The discourse extracts that allowed us to answer the research questions were selected, and the results obtained from the independent analyses of three researchers were contrasted.

4.3.4.4. Chain of evidences

a) Which indicators define the success of the family planning programme in the PHC Polígono Sur?

All PHCs in Spain are responsible for aa family planning programme addressing the needs of the particular community they serve. However, this programme is developed differently in each centre. As one practitioner states:

"Usually, each centre has its own family planning programme, but in some centres there is only one professional, or the programme has been suspended and in this case the family doctor provides care for a specific community... We consider that in this area the programme must be especially reinforced, so we really take care of it."

(Doctor 1)

All the providers in the centre consider that the programme is indispensable due to the vulnerability of the social group to which it is addressed. It has been running for almost twenty years in the centre, and it has developed different operational methods throughout this time. One of the practitioners recalls the beginnings of the programme as a failure:

"At first there were times when all I wanted was for June to arrive so I could leave on vacation. I could not stand the fact that the same patients underwent several abortions (...), and that was something that really killed me, because I felt that the programme was such a failure."
(Nursing Assistant 1)

In contrast, nowadays, providers are more optimistic regarding the success of the programme:

"I can see it because there are fewer pregnancies now, which means that, leaving the economic situation aside, this decrease is also due to family planning. As a midwife, I monitor users, and so I can see that the programme is working."
(Midwife)

The efficiency of the programme can also be seen in the cases in which mothers teach their daughters the necessity for family planning, just as they once learned:

"You see that mothers bring their daughters before they get married, and mothers-in-law that bring girls before they have intercourse (...). Because they get married at a very young age, don't they? When they are just 14. So, this is motivating"
(Nurse1)

The users that were interviewed openly declare their satisfaction with the family planning programme. Especially, they praise how practitioners treat them:

"We come here because they really care... That's why. In the other hospital you are not treated the same way, they are crabby, the doctors there."
(User 2)

"Here they help you, and the midwife, when I was pregnant, told me: 'When you have your baby, just come along and we will give you contraceptives.' They help with family planning, they give us injections, or they prescribe what they consider good for you, or they tell other doctors to provide you with an IUD."
(User 1)

Also, these women patients value the fact that providers make great efforts to be flexible:

"Here, they really understand us, they know us, our circumstances (…). Even without an appointment, we come here and they try hard to see us."
(User 2)

In general terms, they value their participation in the programme:

"I have come all these years, perfect. I can say I never had a problem here."
(User 3)

"Everything is fine with me since I come here."
(User 4)

The level of patient satisfaction and their responses to the programme are reflected in the motivation and satisfaction of the providers, particularly in the case of the midwife of the program:

"I am happy, because I think I have achieved many things, mostly with monitoring during pregnancy and postnatal care (…). I offer support for these women's family planning (…). I have my patients' respect (...) I am getting them to do the follow-ups (…). I am very satisfied because they come looking for the midwife all the time, morning or evening, they look for me. I feel that they need me, that I am useful to them."

(Midwife)

b) What are the challenges regarding the Roma population in terms of family planning?

The first challenge that providers are faced with is that patients generally lack the necessary documentation to apply for a Health Card in order to be assisted as full citizens within the NHS. Although all the providers declare that they never refuse medical assistance to people without a Health Card, they acknowledge that this makes the process very difficult (e.g., they cannot have access to medical records, or prescribe proper treatments). These administrative barriers regarding the access to the health system are highlighted by one practitioner:

"For me, the main difficulties are administrative, because these people don't usually do their paperwork (…). Many young people don't even have an ID card. Many pregnant teenagers don't have an ID card. There was the case that one of them was missing from all the records, as sometimes they don't even have a birth certificate."

(Midwife)

Another characteristic of this social environment is that many of the Roma assisted by the PHC are travellers. This is a great challenge for practitioners, as it is difficult to establish a close and long-lasting relationship with patients. In their own words:

"Something that characterises this centre is that people who have normalised their lives suddenly move to a different place, and then comes another person with a dysfunctional family background. Then everything has to start afresh."

(Nursing Assistant 1)

"The travelling population represents a high percentage of the users, they come and go, and this affects your work. If there is an incident or something, we suddenly notice a gain or a loss of patients."

(Doctor 1)

One of the major challenges that providers highlight is the lack of family planning as an intrinsic characteristic of the Roma population they assist:

"The field of contraceptives or family planning is unfamiliar to them; they don't have this planning culture, not even for nutrition (...). Whatever requires planning is a big effort for them."

(Nursing Assistant 2)

Thus, providers observe that women patients only realise they need contraceptives when it is too late - that is, when they are already pregnant. The same happens when they deal with treatments that have no immediate effect on the pain that patients are suffering from at the time:

"Medication must be something that shows some effect. If they don't see this effect, it is very difficult to convince them to take it. In fact, chronic diseases are much more common in this population than in others."

(Doctor 1)

This lack of future planning generates inconveniences for the Roma users as well as for the centre's appointment system:

"You give them an appointment in a month's time, you give it to a person who has no watch, no calendar. And, in a month's time, this person could be selling in a market somewhere or doing whatever."

(Doctor 1)

This results in a high number of missed appointments, while at the same time many users go to the PHC at any time, expecting to be seen without an appointment.

Along with this, practitioners also highlight certain peculiarities in the Roma population's access to healthcare services. For example, they have observed that this population often go to the centre for minor issues:

"Here, they come to the doctor's for everything. If they have a common wound, they don't buy a sticking plaster or Betadine, they come to the centre to get it cleaned."

(Doctor 1)

However, specific symptoms of certain diseases that these women suffer are disregarded, and therefore they do arrange check-ups to treat them:

"Roma women assimilate aging quite soon, they accept early aging, so there are symptoms they are not going to tell their doctor about because they think it's normal (…), for example, urinary incontinence. They will never tell you about it."

(Doctor 1)

Finally, a challenge that is always present when working with Roma population is poverty, which prevents patients from being able to pay for treatments or prescription contraceptives (the NHS partly subsidises prescription drugs, but patients must pay a small part of the total price). The price of drugs is, then, one important aspect that practitioners bear in mind when issuing prescriptions:

"We prescribe Adepo in most cases, an injectable contraceptive that lasts for 3 months, and each dose is roughly a euro. Most people in this area don't carry any money with them, they don't use any money at all."

(Doctor 1)

In response to this critical situation, some social and religious associations offer some medications for free. Many women go to these "charity drug banks" to get contraceptives:

"In this area, drug banks are widely used (...), not only by undocumented people, who are not as many as those who don't have any money. Now I am starting to prescribe considering the price of some treatments, because patients ask me: But how much is that? (…) And then they go to Cáritas to get them."

(Doctor 1)

c) What skills and strategies have health practitioners developed in order to efficiently tackle these challenges?

Health practitioners in charge of the family planning programme in the PHC Polígono Sur have become very aware of their needs as providers and as a public institution to adapt to the particular features of the community they assist. As one practitioner states:

"I am going to provide health assistance to a population with particular characteristics. I think that healthcare should adapt to the people for whom it is provided. If this community demands immediate assistance, then what's with giving appointments in a month's time? The service must be adapted to suit the characteristics of the population."

(Doctor 1)

As a consequence, they have developed a series of practices throughout the years: **Practitioners adapt certain clinical protocols to the population they assist**. For example, regarding the prescription of contraceptives after childbirth:

"We also adapt some contraceptive protocols. For instance, in the forty-day period after childbirth contraceptives are not generally prescribed. The Roma community is one of the few where we do it, we prescribe contraceptives, because it is one of their customs (...) to have full sexual relations very soon, and some women get pregnant within one month of childbirth."

(Doctor 1)

They also adapt the way routine gynaecological examinations are carried out:

"Many times they stop coming because they think that in order to get the pill or something else they have to undergo a smear or a pelvic exam, and they don't (...). And so, at first, we don't do any examination."

(Doctor 2)

In order to adapt to the lack of formal education of the majority of the population they assist, practitioners make **great efforts to communicate relevant information orally to users:**

"This population can't read, written information is the worst, so we don't use it."

(Doctor 1)

Practitioners are aware that their role is not only to provide certain services, but also to provide education in reproductive health:

"I organise workshops on maternal education, where we deal with health topics, with family planning. Then there's also my postnatal workshop, where I also get them engaged. I know this

work because I try hard so they don't drop out: I give them appointments, I see them and I keep preparing them, educating them."

(Midwife)

Furthermore, the midwife also visits the local school regularly to teach teenagers about contraceptive methods and sexually transmitted diseases. In spite of all this, practitioners also acknowledge that this is a complex, long, and slow process:

"It takes a long time and a lot of energy to explain everything to them until you think they have understood. But then you see them in the blood collection service, and you know they haven't understood a thing. (...) But we have to educate them, don't we? (...) and there and then I try to engage the patient and educate her so she keeps taking steps in this direction."

(Nursing Assistant 1)

Practitioners have developed what they call "opportunist engaging" - that is, they try to engage a user of a different programme in the centre and transfer her to the family planning programme:

"What I do is mainly active engaging. Not only when I am in family planning, but also when I am in any other service or in the accident and emergency department, because this is a group that does not regularly follow preventive programmes of any kind, because they don't think it's necessary (...). Opportunist engaging is essential."

(Nurse 1)

"We try to engage them even on the corridors (...). We even do it outside service hours."

(Nurse 2)

One of the key moments for engaging new users is at pregnancy tests:

"We established that, if an urgent pregnancy test is requested, the result is not given to the woman immediately. Rather, she has to see the doctor first, who transfers her to the midwife so she can engage her in the programme or address her regarding contraceptive methods."

(Nurse 2)

As far as "opportunist engaging," practitioners' **monitoring of users is very personalised**, and they stress that they use the telephone to contact them:

"I use the telephone a lot, I call them a lot. I call them when they miss an appointment. Sometimes I also go to their places to look for them, so they can have a proper follow-up."

(Midwife)

All the practitioners agree that this community requires very active and consistent monitoring, in order to ensure the continuation of treatments:

"How do we do it? How do we adapt? For example, we know that it is not simply a question of giving an appointment and then you can just sit and relax (...). We are always watchful, always (...), and we call them and we ask them about their activities: Are you going to set up a market? When are you leaving?"

(Doctor 1)

Practitioners have developed **great flexibility to facilitate Roma population's access to medical care:**

"I think that making it easy for people to access the programme is very important."
(Nursing Assistant 2)

In fact, it is not compulsory to arrange an appointment to be seen; they try to assist them as they go along:

"If there is a problem related to planning, they don't have to wait so much, we assist them on the go (...), we even assist them on the corridors, like 'come over here to this room and see such and such doctor.' And they go there and a method is prescribed."
(Nurse 1)

Moreover, practitioners take their patients to their fellow practitioners' rooms in order to facilitate referral and so that they can be assisted promptly:

"If, in a postnatal appointment, the midwife learns that intercourse has already been resumed and that the woman might get pregnant again, even if it's only within twenty days from childbirth, she calls one of the doctors so that something may be prescribed straightaway. That woman can be seen straightaway, she doesn't need to arrange an appointment."
(Doctor 1)

As can be seen, there is **a great degree of collaboration among practitioners**, who find that teamwork is the best way to tackle the complex social reality that they face:

"We have been trained together; we have become aware of the need to be coordinated, beyond what the planning programme requires from us."
(Midwife)

Although each healthcare professional has a specific role, all of them take care of users to the same level, especially when it comes to opportunist engaging:

"All the staff is very much involved in everything. Because, if her patient is a woman with three children, she will immediately tell her: listen, have they been vaccinated? The same with me, I mean, we do everything, we try to engage them from any of the programmes."
(Doctor 1)

At the same time, two providers who are not involved in the family planning programme liaise between practitioners and other CSOs and public institutions in the area:

"The social worker and the laser nurse are generally involved with the city council. This neighbourhood has to work as a team; it has to be interconnected (...). Those people act as a link."
(Doctor 1)

That way, they manage to have a broader view of the social problems that they face, and of the actions that are carried out from different areas.

Practitioners have been able **to develop a series of skills that help them tackle efficiently the problems that they face at work and ensure the success of the family planning programme**. Among these skills, practitioners highlight:

(1) **familiarity with users*:***

"I think familiarity, we are very approachable (...). I think that it is very valued here, for example, if you know their family: 'Well, you know, I am going to treat your grandfather.' And many times it is through the family that we get to engage the person, either for planning or vaccinations."
(Nurse 2)

(2) **empathy towards the users' personal circumstances:**

"A little bit of empathy is good, to put yourself in their shoes, to know what they've had to live through, the society where they have to live, they haven't chosen it, and well, sometimes it is exasperating, but some other times, this is precisely what makes you aware of things, isn't it?"
(Nursing Assistant 2)

(3) **resoluteness in the face of everyday problems:**

"To have a calling for solving problems, right? To solve problems (...). What's the problem? (...) Let's do it, right?"
(Nursing Assistant 1)

and (4) a **positive attitude towards other cultures:**

"It's like an attitude or a capacity to be constructively amazed. For me, the Roma community is very different from me, I consider them different, but they amaze me constructively, I don't know, I like seeing those differences (...). That is very gratifying for me, it is something that I find gratifying. I think that if you have that curiosity, well, then your job becomes more logical and interesting, because sometimes it's a bummer, of course, because there are many little failures."
(Nursing Assistant 2)

As a healthcare organisation, **the PHC itself has made several adjustments in order to adapt to the characteristics of the population that it assists**. Thus, the practitioner-patient ratio is lower in this centre than in other areas of the city, because they understand that work here is more demanding. Furthermore, the family planning programme is open three mornings and one afternoon every week, because of the little availability of the Roma population to adjust to the schedules provided by most PHCs:

"In the morning, the women generally go to the street markets, and so they would never attend the programme."
(Doctor 1)

Lastly, the centre is open for training programmes meant for its healthcare providers to improve their competencies, especially with respect to how to deal with the Roma population:

"Members of Fakali have come here to deliver talks (...). They've come here to tell us about their life, their way of being, their feelings (...), what they feel is their people. They've talked about the history of the Roma people."

(Midwife)

d) What elements are considered challenges that still need to be faced?

Even though the family planning programme is considered successful by providers and satisfactory by users, practitioners are aware that many challenges remain.

In the first place, they believe that there should be a medical record specifically designed for the Roma people. With a record of this kind, they could carry out quantitative assessment of how effective their family planning programme is. Without a record, the assessment of the programme is limited to the practitioners' perceptions, which generates some uncertainty as to the actual efficacy of the programme:

"We do our best, we do what we can, that's true. Then the results will be what will be, but very often we don't know them."

(Nurse 2)

Secondly, practitioners still see Roma teenager pregnancy prevention as a daunting challenge, due in part to cultural values, much ingrained in this population, which have proven difficult to modify:

"It is very difficult to prevent 14-15 year-old girls from getting pregnant (...). It's easier when they are older, but it is very difficult to prevent the first pregnancy (...). For Roma girls, well, for many of them (...) it is very important to get married and have children and the sooner the better. They even ask for fertility tests at 17. If they don't get pregnant soon, they start thinking that they are sterile and that they need a test (...). In these cases, we don't know how to proceed, because it's a cultural thing, and very difficult, isn't it?"

(Doctor 2)

Finally, practitioners think that work with Roma men would be a necessary complement to their work with women. Nevertheless, so far they have not managed to get them involved in the process:

"Roma men are very difficult, they don't get involved in anything, many women even come here to get contraceptive methods behind their partner's back (...). Men are in worse health conditions, much worse than women, they let themselves go (...). We always treat women, but it is culturally very difficult to approach men."

(Doctor 2)

4.3.4.5. Lessons learned

There are several reasons for considering the family planning programme implemented in the PHC Polígono Sur as an example of good practice in work with the Roma population: (a) practitioners are capable of developing the necessary ***competences*** to assist their users adequately, adapting to their peculiarities as a people, and to satisfactorily manage the stress conditions and the adverse social situation in which they work; (b) ***professional practices*** have been adapted to the characteristics of the population, especially regarding clinical protocols, active engaging and personalised monitoring;

(c) there is ***close collaboration*** among the healthcare providers involved in the family planning programme, as well as between these and other social agents in the area, something that gives them a wider view of the social problems that they face; and (d) the ***healthcare organisation is sensitive*** to the peculiarities of the population it assists, concerned with the training of its providers, and capable of adapting to the demands for improvement of its members.

The information drawn from this case study is helpful for adapting the design and implementation of healthcare practices to the characteristics of the Roma population in other similar contexts. Specifically, the most important lessons learned from this case study are the following:

- It is important to be aware of the fact that **being of Roma origin generally goes hand in hand with poverty and a low level of education**. This fact evidences the need to consolidate a coordinated network of intervention stakeholders (e.g., providers within the public administration, members of social organisations, practitioners and technicians) to work simultaneously on different levels (e.g., educational, social, cultural, professional and public health).
- Bearing in mind **the central role that women have in care processes**, it is important for CSOs to create workshops to train Roma women in symptom recognition, personal and family care, and such similar health issues.
- It is essential **to privilege the concept of prevention over the concept of treatment**, especially in the information given to Roma children and youths in schools.
- It is an innovative and interesting measure **to locate Roma men who can become referents of healthy habits for their community**, in order to promote these also among the male population.
- The recruitment and **training of human resources** to work directly with Roma people must include the following skills: **familiarity, empathy, resolution skills in adverse situations and openness to other cultures and worldviews.**
- It is necessary for healthcare providers **to play an active role in the situations of vulnerability** with which they deal, constantly engaging new patients and personalising monitoring through home visits or telephone calls.
- There is a **direct relationship between users' satisfaction and providers' motivation**. Therefore, it is beneficial to provide practitioners with feedback that shows the users' satisfaction with their performance.
- In work with the Roma population, it is important for **professional healthcare practices to remain flexible and to adapt to the particular characteristics of Roma population** (e.g., adaptation of clinical protocols, oral transmission of information, morning and afternoon shifts for user assistance services, and so on).
- It is necessary **to simplify the administrative procedures that ensure medical assistance for the Roma population**. In order to do so, a person of reference in the centre should be in charge of dealing with the required documentation.
- **The implementation of an efficient appointment system** is needed, with limited waiting periods adapted to the Roma patients who are travellers.
- In order to acknowledge the work of its professional, **the healthcare institution must lower practitioner-patient ratios and provide constant support through specific training programmes**.
- **Healthcare organisations must encourage teamwork and implement reward systems that promote cooperative work** over competitive work. This is the best way to deal with professional stress and to offer a quality service.

- It is important **to implement an assessment system** that, without obstructing their work, may allow practitioners to assess the real impact and efficiency of healthcare programmes.

Box 7: Highlights of responsiveness of healthcare services

The NRIS and its Operational plan cover the responsiveness of the NHS through the objectives aimed at reducing specific Roma health inequities and the strategic lines of actions to do so (such as use and efficiency of healthcare services). However, attention has been drawn to the limitations of the NRIS in this way:

- It is mainly focused on the national Roma population, disregarding the foreign Roma community.
- Its perspective is exclusively biomedical
- Its objectives are neither interconnect nor integrated with other existing policies and strategies of the NHS.

Some efforts have been done to make the NHS more responsive towards the Roma community:

- At a policy level regional and national governments have developed plans to culturally train providers, published reports and guides about Roma health, culturally adapted campaigns, deployed health agents (e.g., Action Plan for the Development of the Roma Population 2010-2012, or the I and II Integrated Plan for the Roma People in Catalonia. However, nothing of the above is integrated in the academic curriculum of health degrees.
- Generally, healthcare centres do not have specific protocols for the Roma. Although some of them adapt the general protocols to their Roma population and needs.
- Some of these adaptations are related to the ways to communicate with Roma users, balance healthcare assistance with their religious beliefs, economic situation, etc.
- There are also other adaptations that imply a great effort on the part of providers, such as being more proactive, constantly vigilant on monitoring and locating Roma users; which can cause burnout among providers.

4.4. Achieving and sustaining change

The NRIS Operational Plan focuses on the need to improve the coordination and collaboration among different stakeholders (Ministry of Health, Social Services and Equality, 2013). Their coordination will be central for the planning and guiding of state general administrations and the AACC. To ensure its success, this plan proposes a series of changes to overcome the difficulties encountered in previous projects, including the promotion of policies and actions intended to reduce the inequalities in health of the Roma population and to have more equitable healthcare services. In this sense, special attention must be paid to the foreign Roma population. Therefore, this plan requires the active participation of the Health Working Group of the Roma State Council in all its actions. At the same time, the plan also guarantees collaborative work among the different agents involved, reinforcing inter-sectoral, multi-territorial and institutional collaboration.

In this regard, this report considers the following indicators: (1) the political and economic context of the NRIS; (2) the challenges regarding Roma collaboration and participation, including the relationships between national and foreign Roma, Roma associationism and the collaborative relations among organisations; (3) collaborative work among the different agents involved, placing

the focus on the impact of the power relations between them; (4) the promotion of inter-sectoral collaboration and the synergistic role that health promotion plays in this sense.

4.4.1. The political and economic context of the NRIS

One of the challenges that could hinder the implementation of the NRIS in Spain is the current unstable economic and political climate characterized by cutbacks in public protection services such as health or education. This difficult situation not only limits the distribution, planning, and recruitment of human, economic and material resources, but also reduces the impact of previous achievements in Roma health. As a matter of fact, it is important to highlight that the NRIS in Spain could not be implemented in 2012 and 2013, since the Operational Plan was not developed until the mid of 2014 –when this report was already being written.

At the same time, the fact that the strategy is not sufficiently publicised among stakeholders and civil society alike also hampers its correct implementation. More specifically, the NRIS is known within national and regional institutions because it is compulsory for proposals for funding to be correspondent with existing national and European projects—it is for this reason that the future comprehensive plans for the Roma population in Catalonia and Andalusia incorporate the objectives of the NRIS. However, **at local level, the strategy is hardly known**. Some stakeholders are aware of its contents, but because the information has come from other sources (e.g., websites and CSOs' reports).

The interviewees, who work more closely with the Roma community, blame their ignorance of the NRIS as well as its deficient implementation on the **little commitment and interest among those in charge of the strategy.** They also highlight the **lack of shared responsibility among multiple stakeholders** in making the strategy fully functional**:**

"We [providers and policymakers] are also responsible; they [the Roma] do what they can."
(Social Worker4)

The lack of information, coordination, and communication among stakeholders may be due to the **decentralisation of the competencies of the NRIS to national, regional and local institutions, which makes the accountability of its implementation and monitoring unclear.** As a matter of fact, the NRIS is an initiative of the Spanish Ministry of Health, Social Services, and Equality (*Ministerio de Sanidad, Política Social e Igualdad)* which works in coordination with other ministries and delegates responsibilities to the AACC, in charge of implementing the strategy through regional plans. In order to assess this decentralisation of competencies, there is a group of technical cooperation made up of representatives of the NRIS in the Ministry and policymakers in the AACC. From that point, the process of implementing the strategy encounters a series of difficulties. Firstly, because regional bodies also delegate powers to local institutions and this may generate a conflict of interests (e.g., if the political party that governs a city council is different from that of the regional government). Secondly, because **the NRIS does not have its own budget, but rather gets funding from existing budgets** (e.g., the budget of the Roma Development Programme, Personal Income Tax, national benefit schemes and European funds):

"Writing plans down is not expensive and it makes them look good, but developing everything that has been written down is expensive and that's when plans begin to founder."
(Policymaker1)

As a result of all this, the government cannot, either from a political or administrative position, force regional and local governments to implement a plan that does not have its own budget:

"The Spanish government has created a project that does not contemplate funding. In order to implement such a specific strategy, funding is needed."

(Policymaker1)

This means that national plans and strategies are only carried out when regional or local governments deem it appropriate. In other words, if any AACC wants local government or organisation to implement the NRIS, they have to make these objectives eligible for public funding. In conclusion, economic limitations and those related to coordination may have a negative impact on the implementation and sustainability of the NRIS.

4.4.2. Associationism, participation and collaboration of the national and foreign Roma communities

The participation of the national Roma community in the political and social spheres has evolved positively in recent years and the associative movement has gained momentum. Nevertheless, there are still some challenges in this respect. The first challenge is that there is still institutional discrimination against Roma people, especially against foreign Roma. This is reflected in their complaints about the lack of people of Roma origin in associations' and institutions' executive teams, and lack of representation that is worse when considering the case of women and public institutions. In these, Roma involvement is often restricted to collaboration in working groups or counselling activities:

"In public institutions, positive discrimination is not possible. A different thing is if they apply for these positions or if the programmes applying for funding contemplate this kind of measure."

(Policymaker1)

Consequently, stakeholders are concerned that it is non-Roma people who are mostly in charge of designing and implementing actions addressed to the Roma community, a fact that, in spite of their good will, has poor results. Considering this, the Roma community demands collaborative work where Roma people can play a central role:

"It is very important for the Roma community to become involved and participate in all the actions, and we welcome all those who want to help."

(Policymaker2)

At the same time, the breach of the personal data protection act (Organic Law 15/1999) as well as the European Directive on this issue, prevents knowing the exact number of Roma people in the country and knowing whether existing estimations include both national and foreign Roma (Laparra, 2007). This entails the invisibility of the Roma people in plans and strategies, which means that actions are not developed in accordance with their needs (La Parra, Gil-González, & Jiménez 2013). All this affects foreign Roma more acutely, since neither their community nor their settlements are acknowledged by the system. For example, some local governments refuse to register this population in the census as this would imply the recognition of a problem and the assumption of the responsibility to address it:

"If a child is born in El Vacie [foreign Roma settlement in Seville], she cannot be registered as a Spanish citizen because this is a zero-growth area. If they start registering them, the census goes from 3,000 to 6,000 people, which means that more money, a larger space and institutional help are needed (...). And what they are doing now is precisely cutting down expenses."
(Mediator1)

This sort of discrimination has worsened since Bulgaria and Romania joined the EU, which left foreign Roma people in institutional limbo, as they cannot longer benefit from the resources and services addressed to the foreign population. At the same time, the resources and services addressed to the national Roma population have not been reassigned to ensure that competent bodies (i.e., social services) continue to assist this minority. The system considers them as immigrants:

"So, what are they? They are immigrants, but from member states, with full rights (...). So, they should be assisted by the administrations that deal with people from ethnic minorities"
(Policymaker1)

According to some stakeholders, the second challenge that Roma associationism faces is the fact that many national Roma population and associations do not sympathise with and even discriminate foreign Roma. This means that they do not see themselves as belonging to the same community, something that creates further breaches between both groups:

"There are Roma people who believe that they are all Roma and that they are all equal, regardless of where they come from. However, there are others who feel more Spanish. Foreign Roma suffer double discrimination in this sense."
(Mediator2)

"When there is an international forum, Bulgarian, Romanian and Polish Roma speak their native language, Romani; Spanish Roma don't."
(Social worker1)

As a consequence of this, there are complaints about the national Roma organisations' disregard for foreign Roma, and about their lack of awareness of and concern with this population:

"Well, regarding Eastern European Roma, all we know is that we know nothing about them. (...) There is willingness to know, but not beyond what we already know: that they come in families, that they settle somewhere [and] that they travel from one place to the next."
(Manager5)

This lack of information may hinder even further the inclusion of foreign Roma health within the objectives of national Roma organisations:

"If it's difficult to find people dealing with the health of Roma people, imagine how difficult it is to find somebody working on the health of foreign Roma community."
(Mediator2)

This discrimination of national Roma against foreign Roma is reinforced by public bodies that promote plans and grants exclusively addressed to well-organised and well-established associations—which are mainly national Roma associations:

"Institutions award grants to provide resources, but we know we can't give [grants to national associations] if we want to help the foreign community (...) because they are not going straight [to them]."
(Policymaker4)

At the same time, collaboration and organizational association between foreign and national Roma is practically non-existent, due to the fact that inclusive social networks are not promoted and that the disastrous living conditions of the foreign population does not make it easy for them to unite:

"It is very difficult for people in such a precarious situation to get together, isn't it? Sometimes you need to cover some basic needs to have the energy to do it."
(Manager1)

As a result, foreign Roma lacks of formal associationism and the collaboration among them is often casual:

"There are support networks (...). I've seen families of scrap metal collectors who have managed to get the money to repatriate the body of a relative thanks to the help of the community. This is for me a form of association, a form of collaboration. The thing is that these are not formalized."
(Social worker1)

Finally, there is a progressive and dangerous process of bureaucratisation of Roma associations:

"Is the associative movement representative of the population? Or is it representative of its affiliates and members?"
(Manager1)

According to interviewees, the national Roma community must not be the only interlocutor when working with the foreign Roma population:

"National Roma associations should represent all the Roma, but they don't."
(Manager5)

Interviewees also believe that organisations need more people who are more: *"capable of siding [with the Roma community] while maintaining professionalism"* **(Policymaker4)**. In order to do so, it is important to have interlocutors within the community, such as service providers that work directly with Roma people. Furthermore, recent cuts in material and economic resources has resulted in a competition for such resources –especially in situations of exclusion where goods are scarce—that further hampers collaboration between national and foreign Roma:

"In Badalona, there is now a very xenophobic campaign that is, I have to say, brainwashing national Roma against foreign Roma."
(Mediator2)

This kind of rivalry is also present among national Roma associations that compete for resources and, consequently, only work for the benefit of their own communities and the continuity of their programmes. This implies that many of them cease to represent some sectors of the national Roma population itself:

"Now that, to be honest, there are cuts in resources for everyone, the general tendency is towards overprotection and ensuring the continuity of what you do."
(Manager5)

"Association also has its limits, right? It's not all the Roma, but those who, for one reason or another, have joined forces to get a grant, or to get a job, because they really want to improve their conditions. But association within the Roma population is generally quite limited."
(Manager1)

Also, this has resulted in clientelism between associations and administration, and between users and associations, which promotes a subsidy culture and a culture of poverty that stigmatises this community when it should be empowered:

"We have created a series of patronising aids, a sort of charity. We've reached the point when we confuse Roma culture with living on benefits. This is not Roma culture! It has been easier to give them money than to empower them, than to work with them (...) because this is a slower process and the results take a while to be seen."
(Mediator1).

All these issues are undermining Roma associationism, hindering the creation of a solid system to encourage all the sectors of the national and foreign Roma community to take active part in the process of improving their health status.

4.4.3. Collaborative work among multiple stakeholders

Collaboration among different stakeholders generally takes place on two different levels: a horizontal level, where collaborative work is carried out by people or organisations at the same level (e.g., service providers); and a vertical level, where collaboration takes place among stakeholders from different levels (e.g., providers and policymakers).

Horizontal relationships between organisations and providers that work closely with the community (e.g., schools, primary care centres and social organisations) are generally highly regarded. An example of this is the creation of strong social fabric through community roundtables, working groups or networks that develop activities to improve the health of the Roma population (e.g., locating people, health education workshops, visits to settlements, promotion, and training). The main problems at this level emerge from the **lack of coordination among different stakeholders**. This gives rise to situations in which, for example, several organisations work independently on similar programmes in the same areas, something that wastes resources and produces uncertain results:

"Yes, it's true, sometimes we are not coordinated. They ask me to give talks here and there, but they don't get together so we can address a whole lot of women. Each association requires you to do something."

(Healthcare provider1)

Also, horizontal relationships on higher organisational levels (i.e., between regional institutions in charge of implementing plans and strategies) often happen through official participation bodies such as committees or governments' interdepartmental groups. The difficulties in these cases are mainly due to budget issues, but also to the fact that these **meetings are not frequent and to institutions' lack of involvement and interest in Roma issues**.

Vertical relationships between community organisations and highly hierarchized/politicised institutions are often difficult. Stakeholders who work directly with the community complain about the lack of awareness of the Roma population, and the deficient communication, collaboration and commitment of institutions. They also complain about **institutions' passivity** and **lack of a proactive involvement regarding stakeholders' needs**:

"I think that among us [providers], who work directly with them, there are no problems. As a matter of fact, we know each other and we have good relationships (...). We are often in touch and we speak the same language (...). It is in the more institutional, more political, dimension that problems arise and collaboration is scant."

(Mediator2)

4.4.4. Promoting inter-sectoral action

In order to facilitate this collaboration, Roma associations and CSOs participate in periodic roundtables and meetings with government institutions, as well as in national and international conferences that favour dialogue between different stakeholders and facilitate the implementation and assessment of different programmes and strategies. Also, at national and regional level, plans to promote collaboration have been developed. In this way, the Roma Development Programme in 1989 and the creation of the National Roma Council in 2005, promoted the participation of the Roma community, their association and networking with different agents. Indeed, the Council participated in the elaboration of the National Action Plan for Social Inclusion (2008-2010), defending the need to mobilise institutional bodies and agents at different levels (e.g., AACC, CSOs, etc.) to achieve Roma integration. Also, the Action Plan for Development of Roma Population (2010-2012) involved the Roma community in the design, development and assessment of actions intended to reduce health inequities, drawing attention to good practices and promoting the creation of inter-sectoral spaces to foster dialogue and disseminate findings. This plan emerged from the process of bringing together the plans of different ministries. Currently, in Andalusia, the Ministry for the Roma Population (*Secretaría para la Comunidad Gitana*) is a body that advises and coordinates the actions directed to promote the Roma community. The Integrated Plan for the Roma Community of Andalusia (1996) encourages the active participation of the Roma community, both individually and collectively, through sensitive plans and policies, health education programmes and the training of providers. In Catalonia, the first and second Integrated Plan for the Roma People includes the incorporation of Roma providers into the CatSalut system and the ASPCAT.

4.4.5. Case study: Inter-sectoral working model for improving the participation of Roma women in prevention and health promotion programmes

4.4.5.1. Background

La Mina neighbourhood is part of the Sant Adrià de Besòs district of the Barcelona metropolitan area. It is located in the south-west corner of the municipality, separated from the city centre by the River Besòs, the Ronda Litoral coastal ring road, a railway line and La Catalana neighbourhood. In recent years, the areas bordering La Mina neighbourhood, especially the Fòrum area and the last section of Avinguda Diagonal have seen redevelopment with a new hotel, leisure, sports and commercial activities, which has put La Mina back on the map of the Metropolitan Area of Barcelona. For decades though, it had been physically isolated, cut off by industrial areas and others with no fixed use that were quickly turned into dumping grounds and prevented the exchange and connection of the residential area of the neighbourhood with its surrounding environment and the waterfront.

In 1969, the Barcelona Municipal Housing Board bought the land on which La Mina neighbourhood was built from the Town Council of SantAdrià de Besòs. The transaction was intended to eradicate various shanty towns that had sprung up in different parts of the municipal area of Barcelona City (i.e., Camp de la Bota, Somorrostro, Pekín, La Perona, Can Tunis and Montjuïc) as a result of the high numbers of migrants entering Catalonia. The bulk of occupation took place between 1973 and 1974: by 1975, 15,000 people were living in La Mina.

Due to the way in which it was designed and the unique social and urban circumstances of the time, the neighbourhood was marked by:

- Cultural conflicts due to the highly diverse origins of the new residents in a hostile environment for relationships and contact between social groups.
- Deterioration of the surrounding environment due to the proximity of facilities with a strong environmental impact (e.g., power plant, sewage treatment plant and incinerator).
- Lack of resources to improve living conditions and solve the social, labour and economic problems of residents.
- Poor professional skills and part of the population without work, who sometimes suffered from other problems (social exclusion, drug addiction, crime).
- Low involvement of residents in their immediate community environment.

Despite the public investments made in the 1980s and 1990s to address these issues, the lack of coordination between the actions and the difficulty of committing to long-term investment prevented any effective change in the social situation of La Mina. Towards the end of the 1990s, the Town Council of Sant Adrià and the Government of Catalonia, in conjunction with the Provincial Council of Barcelona and Barcelona City Council, launched the Transformation Plan of the La Mina neighbourhood for 2000-2010, which was subsequently extended for another five years (2011-2015), and set up La Mina Neighbourhood Consortium to implement the plan.

The basic aim of the Consortium –as set out in its articles– is to direct, coordinate, and implement the Transformation Plan of La Mina neighbourhood by focusing on education, culture, occupational and social integration, housing, safety, and health prevention programs. These actions are conducted considering that many will have an impact on the health of the population in the neighbourhood as well.

The Consortium is required to coordinate inter-sectoral work in the implementation of social, labour, cultural, educational, health, housing and urban development actions in the neighbourhood.

The social, health, and education resources allocated to La Mina do not fall short in comparison to those allocated to other neighbourhoods. However, more significantly the neighbourhood perhaps lacked a more global project to ensure that the actions different authorities were well coordinated and complementary, and to overcome the dynamic of one-off interventions and short-term aims, as had been attempted several times since 1982.

Thus, La Mina can be described as a neighbourhood of 'instantaneous creation,' a result of the relocation of different population groups originally from other parts of Spain and whose initial services and facilities were soon outgrown by the needs of newcomers, mainly young families with children. In many cases, this population had social, occupational, cultural and/or economic deficits. The number of neighbourhood residents fell from 10,664 in the early 1990s to 8,847 in 2008. At this point, the trend reversed and the population is growing since then. On 1st of January 2014, the municipal register recorded a resident population of 9,777 people aged between 25 and 44 years-old and 27% under 20 years. 51% are men and 48% are women. In this neighbourhood, Roma families live alongside migrant families, Catalan families and those from other parts of Spain.

Sant Adrià is one of the leading municipalities of Catalonia in terms of Roma population, besides Barcelona and Badalona, and La Mina is the neighbourhood with the largest number of Roma residents (Abajo & Carrasco, 2004). Some estimates indicate that Roma make up 30% of all neighbourhood residents (Méndez, 2005: 243). A total of 10% are third-country nationals, particularly from Pakistan, Morocco, and China.

The economic activity of the neighbourhood is based on small local shops with little diversification. Almost half of its businesses (40%) are bars and restaurants. The labour market situation is marked by instability and high unemployment, with significant inequality in access to employment for men and women, to the detriment of women. These issues have formed the cornerstones of the Transformation Plan, addressed by the Consortium of La Mina through its Network of Social and Occupational Integration Services to promote employment and training. Along these lines, the Consortium funds occupational and social integration pathway for women of La Mina neighbourhood project, designed to promote the inclusion of women into the labour market by increasing their motivation to work and accompanying them in developing their professional skills in particular job through technical training at work placements.

There are currently around 30 civil society associations in La Mina, many of which contribute in varying degrees to the improvement and transformation of the neighbourhood. Besides their own activities, they participate in community life by organising various community celebrations over the year to reinforce the sense of belonging. These include Women's Day, Games Day, the Week of Culture, Children's Rights Day, Gender Violence Awareness Day and so on.

In January 2013, the Catalan Government approved the contract to construct the new PHC of La Mina, one of the key facilities of the Neighbourhood Transformation Plan. The works are scheduled for completion in 2014.

4.4.5.2. Research questions

a) What success indicators define the occupational and social integration pathway for women of La Mina neighbourhood project?
b) What are the health problems of Roma women from La Mina and what challenges do they face for the implementation of prevention and health promotion strategies?
c) What skills and strategies have been developed to manage these challenges properly?
d) What elements are considered challenges that still need to be faced?

4.4.5.3. Research process

The information was compiled by three technicians from the Catalan Agency of Public Health (Ministry of Health of the Government of Catalonia). To collect relevant evidence, the following qualitative methods of data collection were used:

- *Documentary compilation:* Analysis of written documents or records cited by those involved in the study project.
- *Participant observation:* Description of what the researchers observed during interviews.
- *Interviews:* Through communicative interaction between researchers and participants, to obtain individual narratives from two of the people involved in the project. Specifically, we conducted in-depth interviews with the project's Roma mediator and social educator.

The informed consent of the interviewees for the recording and use of the data they provided was requested, guaranteeing both full anonymity and that the information would be used strictly for research purposes.

The open questions asked during the interview to the persons in charge of the project included: What does the programme involve? How many women are you in charge of? What health problems have you identified in this group? What do you think the cause of these problems is? Do women participate in prevention and health promotion programmes? What opportunities have you identified and how do you think they could be leveraged? What actions have been undertaken to improve the health of this group through the programme?

The interviews were transcribed and studied in conjunction with the cited documentary material. The fragments of the conversation that could be used to answer the research questions formulated previously were selected and contrasted with the results obtained by analysing the content.

4.4.5.4. Chain of evidences

a) What success indicators define the occupational and social pathway for women of La Mina neighbourhood project?

The project offers a guidance and training pathway. In addition to its guidance actions, group and individual tutoring, work placements and tailored training, the pathway also includes intercultural mediation actions. It is funded by the Consortium of La Mina neighbourhood and seeks to promote the inclusion of women into the labour market by increasing their motivation to work and accompanying them in developing their professional skills in particular to find a job through technical training at work placements. The project also works with Roma women on eliminating labour prejudices and their idea of what non-Roma population thinks about them as a group and as workers.

One of the factors for programme success has been to work with the community to stamp out prejudices and solve problems linked to this. The project seeks to equip participants with the tools to defend themselves and gradually adapt and integrate in their new working environment so that they do not walk out of their jobs. At the starting point, women could not see themselves being able to work because they did not value themselves, and they said that shops would not hire them because they were very dark skinned and would not want them because they would see them as thieves. All based on the prejudices that they thought mainstream society had against them, as if they were coming to steal something, which caused them distress and contradictory emotions that then stopped them from going back to work.

All projects aimed at bringing change at a community level should be carried out with community leaders, in this case with Roma women recognized by their community. This statement is based on the understanding that community recognition is associated with integration and acceptance of culture, codes, and customs.

"To be considered a leader, a professional needs to be in and recognized by their community and to know its codes; otherwise, they are better off working in some other area. (…) Some Roma people work for the community but they are not leaders and they are not recognized by the community; it is important for them to be inside the community so that they understand how it works, because Roma are community based. Community is more important than individuality."
(Mediator)

Another factor to note in this project is its inter-sectoral work**.** The project has used professional reintegration—an activity that Roma women do out of need or obligation—to identify other problems and needs that they do not see as priorities, such as health problems:

"The group of women we are working with on employment issues don't come because they have decided to, they come for practices in the hospitality industry, which is what they are going to do. This is their real aim and through that, we work on other things."
(Social Educator)

In these groups, women are given the opportunity to participate and communicate with the leaders, allowing them to express their views on employment and family, and understandings of health problems. Ultimately, the aim is to address other problems affecting this group, besides employment:

"Because we really believe that to work on health issues we have to work with their needs"
(Mediator)

Another interesting approach to their problems is through the sense of interdependence generated by creating an informal relationship with groups of non-Roma women, which promotes critical thinking by both groups and encourages empathy. Working with the two communities generates space for reflection and integration in which one of the communities focuses on the skills profile of the other – rather than its origin – to increase awareness and generate critical competence. The idea is to create social environment conducive to the processes of communication and collaboration between people from different backgrounds. This interaction facilitate that Roma

women can see their taboos in a different way and relativize them. They can decide to change their attitudes and cultural habits:

"There was a lot of prejudices against them and they got down to work with both groups together, Roma women with non-Roma women, which didn't cause any problems between the Roma and non-Roma women of the neighbourhood."
(Mediator)

"Why do you think that eighty-year-old non-Roma women can get on the underground alone and yet it's unthinkable for our eighty-year-old mothers to travel by themselves on the underground? Because they're at home; they need to be cared for, they're like centenarians."
(Mediator)

b) What are the health problems identified in Roma women from La Mina and what challenges do they pose to the implementation of prevention and health promotion strategies?

One of the main problems identified by the project is unhealthy lifestyle of Roma women. Roma women have unhealthy eating habits and do not get enough physical exercise. Cultural stereotypes are one of the main factors preventing Roma women from taking care of their health; for example, the community does not see exercise as positive. Since doing sports requires women to wear certain type of clothing (i.e. tracksuits) or doing activities in potentially embarrassing postures, it is difficult for them to practise sport:

"Looking after your health is frowned upon among women. Now men are really starting to get out and play sport and go to the gym but women aren't; it's frowned upon."
(Mediator)

Roma women tend to associate health with physical appearance and the absence of illness. Being slim and tanned and having nice skin or hair are the factors determining good health for them:

"What is on the outside is what is valued because Roma people put a lot of emphasis on body image. (...) Being slim is a sign of good health... having nice hair is a sign of good health, having good skin is a sign of good health, being tanned or having a good skin colour is a sign of good health. Being well dressed is a sign that you feel good or are in a good mood... these are the factors that are really valued within the community."
(Social Educator)

Nonetheless, they do not take into account the risks associated with lifestyle habits they adopt to achieve this look:

"What I do is eat the stew my mother-in-law makes at lunch time, that's what we all eat, and then at night I'll have one piece of fruit, otherwise I'll stuff myself on fruit. (…) 'What do I do?' I eat at lunchtime and then I don't have anything else after that. And what do you do not to feel hungry? I go to bed early so I don't get hungry because I don't want to be overweight for the summer."
(Social Educator)

They have health problems linked to the strenuous nature of their work and illnesses caused by their unhealthy habits—poor diet and lack of enough exercise, resulting in diabetes and high blood pressure:

"These women have very heavy burdens; they are working in physically demanding occupations, such as cleaning ladies, and they need physical strength."
(Mediator)

It is very difficult for them to reconcile work and family life, which can lead to depression, anxiety and low self-esteem because they have to meet multiple demands in their day-to-day lives (e.g., employment/unemployment, domestic chores and the family economy, caring for their families and caring for others). Early marriages—with all the family responsibilities this entails—lead to premature ageing among Roma women and health problems associated with their workload and the fact that they are more concerned about others than caring for their own health:

"This is a really hard job, too hard... in women with a triple burden. Here we have women in their forties who are cleaning lots of flats and also have to care for their children, their daughters-in-law, their husbands, their mothers... do you see what I mean? their grandchildren... and there's mental health too; we see that on a daily basis in terms of failure at work and how it affects them; the power of the group is also very strong."
(Mediator)

There is no concept of prevention. Care for them is to go to a professional when the symptoms are already apparent. The providers consider that Roma women have strong tendency to self-medicate:

"Well, naturally, because I'm very tired, my head hurts, because I've got a problem; they take an anti-inflammatory. (…) We are saying that we have a different concept, and our concept is to take care of ourselves when something hurts…" **(Mediator)**

They lack of awareness among providers to tailor prevention and health promotion programmes to the cultural needs of these groups, can be seen in the recommendation of certain activities that are completely off-limits due to cultural barriers:

"Almost every granny has a back pain; they can't move. And what did the doctor prescribe? He prescribed swimming... He told her to go swimming or something... something they can't do. And when I say: 'Why don't you go to the swimming baths?' For them it's impossible. First, they'd have to go alone and grannies are never left alone without someone from their community. They have to wear a cap that we'd be all right with, considering appearance. You have to wear a bathing suit with all the taboos associated with that, when they can go... they don't go swimming. Grannies swim in a housecoat, generally, most of them do."
(Mediator)

c) What skills and strategies have been developed to manage these challenges properly?

One strategy identified as effective by the providers in this project was the need for inter-sectoral work, considering health in a holistic manner dependent on the social environment (e.g., employment, housing, education and the like).

"The service has worked with 173 women in 2013, almost all for employment needs (...) the problem is that behind these needs there are many others, which, on a holistic level, can be social demands and health problems, and they are clearly not going to ask about those here because they know we aren't health professionals. But you can see that not taking care of their health is not doing them any favours."

(Mediator)

This interdisciplinary work has allowed them to identify the health problems and needs of the women attending their professional reintegration programme and to jointly develop intervention strategies tailored to their needs and cultural context. They have managed to optimise public resources for the professional reintegration of this group in order to attract their interest in possible behavioural changes that would allow them to acquire healthy lifestyle habits, which does not appear to be a need for them.

"There is a reintegration part associated with working on the status of individuals, that is, a life project as opposed to a professional project. A life project to empower women in every facet of their lives.(…) So it's a protected environment, which is justified because basically you are looking for work... and if I get home at half past one nobody's going to say anything because I am justifiably working to improve the community, which is looking for work, and my husband is not going to say anything."

(Mediator)

They have created working environment in which Roma women feel comfortable and protected, working with people considered by these women to be leaders in their community.

The project and its providers work to promote physical activity and a healthy diet by adapting the interventions to the cultural context of the Roma community and their understanding of health. For that, the women who started the project used the areas of interest or concept of health among Roma women to design successful strategies in prevention and health promotion (e.g., running out of the neighbourhood in order not to be seen for the rest of the community). If they feel that a particular physical aspect is what determines good health, then it must be used to schedule actions to meet these demands. Physical appearance can be used to work on many other health needs, such as walking, chatting about healthy eating and so on. The important thing, however, is to attract their interest and ensure that they go to these meetings. The project addresses the need to break the taboos of Roma culture with regard to physical activity and raise awareness of the options for practising sport, such as the use of public facilities. There is no need to join a gym if it is not generally culturally accepted.

"So what have we done here?' Actually, a woman from the neighbourhood started to come who was not Roma, and she would do sport every day outdoors, basically running and using the outdoor machines... climbing stairs... and she'd say to us, 'come on, come and join me'. And so we said, quite strategically really: 'All right, we'll join you!' and there was this course full of women but then some were saying 'I'm not running because it's frowned upon', 'I'm not going out because they're going to call me crazy'. So we came up with a plan: we'll go running outside the neighbourhood. We went out in tracksuit and trainers and walked to the Fòrum; nobody walks there – you're alone there – and we run around the Fòrum, where nobody can see us, and we do a bit of sport there. And more women have been joining us, they joined because nobody will see them. (…) Because they can't use

those public spaces they have never been in ... And they don't know what a gym is like inside because they have never been in one... they don't know what the machines are for or what aerobics classes are like."

(Mediator)

The project has set up working groups with Roma and non-Roma women, in which both groups can identify different models from which to learn and set up collaborative – as opposed to competitive – relationships.

"We think it's good to have Roma and non-Roma women, but there needs to be majority of Roma, otherwise they won't identify. And we also believe that there needs to be non-Roma women who already have habits because they are the ones who are going to move the group. Am I making sense? I mean that they will encourage the others... a women who has lost weight and been on a diet will explain to them 'What have you done to get like that?' Some people have certain awareness and encourage the rest. This is the best thing that can happen in a group."

(Mediator)

d) What challenges remain?

- Improve the health of the population through inter-sectoral work, considering the impact on health of any public policy and taking advantage of intervention in one area to identify needs in others.
- The importance of working with and from within the community both on employment issues and on healthcare with referents from Roma people.
- Breaking stereotypes that may adversely affect the health of Roma women, while creating open spaces for discussion but always taking into account the Dialogue between Roma and non-Roma women.
- Preventive and health promotion intervention for Roma women should be tailored to the real needs of these women and their context and lives, so that they can balance self-care with family life.
- We should study and develop strategies for prevention and health promotion tailored to the needs of elderly Roma groups.

The project highlights the need and opportunity to improve Roma health through inter-sectoral work, considering the impact on health of any public policy and taking advantage of intervention in one area to identify needs in others. The project developed in this Roma community is a model for intervention in improving women's health through publicly funded interventions in other areas. The objective is to use an area on interest for the group to be able to use this space as a dinamizator of Health promotion policies that otherwise are no been a priority for Roma women so far, such as to improve their diet and improve her life styles in general. It also highlights the importance of working with and from within the community both on employment issues and on healthcare, which can bring about changes in habits and behaviours in self-care and health promotion. We must work with Roma women leaders from the community if we want to influence change in its lifestyle habits. These referents must know the community codes and rules and must be recognized as members of this community in order to achieve some success. When we deal with sensitive subjects that can break the community cultural rules imposed on women, it is better to begin with women leaders, as Roma women will feel closer and more relaxed when talking about these issues.

The use of leaders (e.g., religious leaders) can be of help when the own community women has already accepted the change.

We are confronting some repetitive processes of habits and stereotypes that can affect negatively the health of Roma women, diminishing their chances for labour market integration and general health improvement. Change must be engendered from inside of the community, and must generate open spaces for debate, while taking into account dialogue between Roma and non-Roma women. Using community referents and creating non-formal spaces for diversity allow the exchange of different points of view and give the possibility for personal growing.

This interrelationship between the two groups may allow them to expand their cultural boundaries and visualize similarities between the two contexts in terms of responses to these problems or making more permeable a possible change in behaviour. An important feature of this type of situation is to enable participants to integrate the experiences of group differences at the same time that they develop different personal identities.

It is also important to work with non-Roma women to create informal spaces for diversity. The interrelationship between the two groups can encourage them to expand their cultural boundaries and see similarities between the two contexts in terms of responses to these problems or making a possible change in behaviour more permeable. One important function of this type of situation is to enable participants to integrate the experiences of group differences while analysing different personal identities.

Preventive and health promotion intervention for Roma women should be tailored to their real needs and their socio-economic realities, so that they can balance self-care with family life. Their behaviours are also dependent on the family environment: whether the woman is a mother, whether she has found employment, whether her husband is supportive and so forth. We must consider the home environment of the individual woman in order to tailor intervention strategies to each situation and incorporate healthy habits and exercise into the lives of Roma women. Community leaders can be made aware of the situation of each woman in order to then work on different strategies. The better and more closely the problem is known, the better and more effective solutions may be applied.

Finally, once the role of female Roma has been analysed, we should study and develop strategies for prevention and health promotion tailored to the needs of elderly Roma groups as a future challenge, since there are few interventions for them within this sector.

4.4.5.5. Lessons learned

The defining characteristic of Roma employment status in Spain is precarious underemployment, although in recent years Roma women have increased their labour participation, albeit below the employment rate of non-Roma women. As a result, many women have been confronted with cultural stereotypes that have led to many difficulties and required efforts for their integration in the labour market.

This situation has led to initiatives such as the occupational and social integration pathway for women of the La Mina neighbourhood project, designed to promote the inclusion of women into

the labour market by increasing their motivation to work and accompanying them in developing their professional skills for particular job through technical training and work placements.

The main reason of Roma women to incorporate themselves to the formal labour market is economic–to help their families–but there is also an interest in gaining economic independence and increase social and personal recognition.

The social determinants of the Roma community bring with them significant health inequalities. Problems with housing, employment and financial resources in general, combined with certain cultural factors, determine their perception of health and their health status. Social and cultural factors influence women's health even more because of the added problems of family burdens and being overworked.

The case described in this report reflects all the evidence published on the situation of Roma but provides us with new strategies for inter-sectoral collaboration to identify the problems of this group and define strategies with a greater impact.

Work, housing and education appear to be much bigger priorities for the Roma population than health promotion, so it is logical that more resources are allocated to these factors. However, we can leverage interventions in these other areas of interest to introduce an interest in or concern for the promotion of their health. We must optimise the resources allocated to Roma to ensure that the Roma community itself changes the way it sees its health and what they can do to prevent health problems.

Within the NHS, there appears to be lack of information tailored to the needs of Roma patients. Prevention and health promotion programmes must take into account the cultural differences of each group and its lifestyle in accordance with the norms of the community.

One intervention strategy with potential for success is to implement communication and information strategies using common spaces where Roma women feel free to talk, in communal areas where they can interact with other Roma women in the same situation or perhaps non-Roma women with whom they forge ties for comparison of interpersonal skills in order to foster critical awareness. This could be done through mediators recognised by the community and focusing on areas of concern for these women, such as their perception of healthiness, their interest in an occupational integration programme or curiosity for a television programme about physical activity.

Roma women should be part of the creation process of prevention and health promotion programs and even in the development of public policies that affect them, both in their design, planning and implementation, in order to detect possible deviations and provide most accurate picture of the community in which they live. It is only through Roma leadership that change can take place.

The information drawn from this case study is helpful for adapting the design and implementation of healthcare practices to the characteristics of the Roma population in other similar contexts. Specifically, the most important lessons learned from this case study are the following:

- **Inter-sectoral policies need to be developed to improve women's health and strengthen their self-esteem.** An inter-institutional approach should be adopted to improve equity in health through health policies that act on social determinants in health.

- **Improve living and working conditions** and generally create favourable environments for health.
- **Focus action on the socio-economic determinants of health in the Roma population, incorporating gender mainstreaming.** Access to education, work, health and improved housing quality are strategic areas, as indicated in the Decade of Roma Inclusion 2005-2015.
- **Increase the participation of Roma women in prevention and promotion programmes** in order to improve their healthy life styles and consequently to have better care of their own health. Thus, they can also have an impact on the health of their families and the Roma society in general due to their caring and referent role for the group.
- **Work with community leaders recognised as members** of the latter who can help negotiate without being seen as an element of pressure and who mediate between the Roma community and the health system.
- **Use meeting spaces accepted by women and the Roma community** in general (e.g., places of worship).
- **Adapt intervention strategies in prevention and health promotion to the needs of Roma women** (e.g., personal, employment, family and cultural context, taking into account their age).
- Focus actions on **reducing the rapid ageing of men and women**.

Box 8: Highlights of achieving and sustaining change

The last fundamental pillar of the NRIS and the Operational Plan is to enhance Roma health through administrative and institutional cooperation and stakeholders´ participation. Nevertheless, some challenges should be highlighted:

- The poor implementation of the NRIS is due to the current economic and political context in Spain.
- The fact that the NRIS does not have its own budget not only limits its implementation and recruitment of resources, but reduces the impact of previous achievements in Roma health.
- The NRIS is not sufficiently publicised among stakeholders and the civil society.
- To carry out its implementation, regional bodies delegate powers to local institutions, thus generating conflicts of interests among the different governments.
- There is a lack of Roma engagement and collaboration in Roma health policy planning.
- There exists institutional discrimination against Roma people, especially against foreign Roma.
- Roma community is concerned that it is non-Roma people who are mostly in charge of designing and implementing actions.
- There is lack of cooperation, coordination and networking among stakeholders, especially in countries of origin (e.g., Bulgaria, Romania).
- The national Roma and their associations do not sympathise with and even discriminate foreign Roma.
- Foreign Roma lack of associations to represent them.
- There is a progressive bureaucratization of Roma associations.

5. PLANNING THE FUTURE

In order to achieve a quality development and implementation of Transformative Roma Health Policies (TRHP), we must take into account that these policies are the outcome of an innovation process that put into practice both evidence-based and discursive approaches. Hence, building TRHP from a multi-stakeholder perspective would be one thing, and implementing them would be another (Frank & Atkins, 1981; Meyers et al., 2012). When planning the future, some challenges may arise, such as the lack of common and shared interests and goals, unrealistic expectations, the lack of evaluation, communication and organizational barriers, segmentation of the network, unbalanced power relations, resistance to change and maintaining the status quo, lack of resources, etc. (Suarez-Balcazar et al., 2007). Bearing this in mind, TRHP from a multi-stakeholder perspective should follow principles to guide the development and implementation of Roma health priorities through specififc community tools.

5.1. Principles

Box 9: Principles of Tranformative Roma Health Policies

- To effectively involve multiple stakeholders by building collaborative capacity.
- To be based on health in all policies and intersectoral action for health perspectives.
- To better monitoring and reporting progress and develop evaluation capacity among stakeholders.
- To redefine the role of the promoters of policies.
- To prevent institutional discrimination.
- To assure cultural competence among stakeholders.
- To institutionalize health mediation.
- To promote health literacy among Roma users.

(1) TRHP should assure **the effective involvement of multiple stakeholders by building collaborative capacity.** Sustaining and strengthening stakeholders' engagement should be an action-oriented process that gives voice to marginalized voices and focus on strengths and capacity building for systems change. The pursuit of systems change often requires engaging multiple stakeholders across multiple sectors in joint action to produce desire and quality changes in the community (Allen at al., 2013). TRHP should adopt a perspective based on the principle of **social justice** by which people may have the resources and skills that are inherent to their rights and allow them to participate in the decision-making process. Significant benefits may arise from this principle. Among the tangible benefits, the NRIS states that **involving and engaging stakeholders—prioritizing the Roma community**—in policymaking is an important health component itself. Besides, it is an ethical and moral imperative: "giving people a voice in matters that affect their lives is an act of fairness" (Prilleltensky, 2014, pp. 152). In addition, it turns Roma stakeholders into legitimate political agents and leaders, thus implying greater effectiveness and recognition for this community within a paternalistic sector that has traditionally assumed the inability of the Roma to successfully lead their own policies (Case et al., 2014). Among the intangible benefits, bringing together all stakeholders will not only entail major changes in the structures and practices of participating organizations, but also in the stakeholders´ attitudes, beliefs and perspectives over time. This will allow organizations to be ready for change, ensuring the successful implementation of innovative measures increasing the resilience of the community. Building collaborative capacity also promotes interdisciplinary work, allowing for advance in scientific knowledge through creative

solutions based on stakeholders' different sensitivities and worldviews. Moreover, the Roma will be progressively included in the lobbies responsible for planning and implementing policies, thus guaranteeing the consistency of policies with their needs as well as the diversification and flexibility their roles. At the same time, the Roma community will increase their health literacy and will become active agents of their health, developing skills and motivation to address health challenges and to defend their rights to promote and maintain good health (Balcazar et al., 2012; Case et al., 2014; Reich & Reich, 2006; WHO, 2009).

(2) Roma health is considered a "wicked problem" due in part to its intersectional nature: the Roma community is not vulnerable due to its ethnic, but also social determinants (e.g., low educational, socioeconomic and employment level) that interact and position this group in a disadvantage situation in comparison with the rest of the society (Bastia, Piper & Prieto, 2011). Therefore, it is required agreed transversal solutions among different sectors in order to tackle effectively the Roma health issue. Consequently, TRHP needs to be guided **in all health related policies and intersectoral actions** by different public policies from different sectors (i.e. education, employment, housing, mobility, justice, culture, environment, etc) collaboratively assume social responsiveness by incorporating the goal of influencing health determinants so as to improve, maintain and protect health (Mannheimer et al., 2007). This vision implies a higher degree of shared responsibility and proactivity which cannot fall exclusively on the Roma, but rather among all stakeholders involved in the health of this community (i.e., policymakers, service providers, the NHS itself, the social context and socioeconomic and cultural conditions have a direct impact on Roma health).

(3) In the same vein, the Jakarta Declaration on Health Promotion highlighted social responsibility for health and the need of a comprehensive, equity-focused health impact assessment at community level, as essential for constructing socially responsible health policies and practices (Mittelmark, 2001). Consequently, TRHP should encourage and assure **better monitoring and reporting progress, and developing evaluation capacity among stakeholders.** Monitoring is key to assess processes and outcomes, as well as to carrying out quality improvement plans and sustainability strategies to ensure the fulfilment of goals (Taylor-Ritzler et al., 2013). Monitoring progress should incorporate traditional evaluation, empowerment evaluation, results-based accountability, and continuous quality improvement that enhance stakeholders' skills while empowering them to plan, implement, and evaluate the program. All this may lead to involving stakeholders in order to understanding and strengthening the implementation of initiatives (e.g. conducting focus groups to assess the satisfaction with policy, monitoring participation of stakeholders), improving the quality of results (e.g. assess if the policy still fits with the needs and goals of stakeholders, assess availability of resources), and meeting accountability and sustainability within the Roma civil society (e.g. creation of a committee, get funding, ensure cross-directional charater of the policy) (Chinman, Imm & Wandersman, 2004). In order to predict and ensure effective monitoring and reporting, it is necessary for stakeholders to be aware of the importance of participatory and inclusive evaluation, to be motivated to conduct the evaluation, and to develop competences to become involved in the evaluation process. At the same time, it is important for the stakeholder coalition to promote leadership for evaluation, to create an environment that fosters evaluative thinking, and to provide resources to support evaluation. Evaluation should be an on-going routine embedded in the stakeholders´ activities and practices aimed at improving Roma health, and evaluation findings should be seen as resources by all stakeholders (García-Ramírez et al., 2009).

(4) The following principle is **to redefine the role of promoters of policies** in order to be **instigators of change, mediators and advocators** of Roma health (Balcazar, Garate-Serafini & Keys, 2004). First, they have **to develop skills** to consider the actions that may most likely achieve the desired outcomes while attempting to address the needs of the Roma population. Secondly, they have **to build trust with all stakeholders** as well as provide mentoring support among the Roma, liaising between the community and healthcare services in order to better access resources and supports. And, finally, **they have to assume the responsibility to guide research and action** towards social justice by developing equity policies to promote Roma health. These roles should be considered in terms of power redistribution so that leadership as well as other values and roles are shared and assumed by all stakeholders, thus enhancing members' critical awareness, information, social relationships, willingness to become involved, interpersonal competences, persistence, experience and advocacy skills (Balcazar, Garate-Serafini & Keys, 2004).

(5) TRHP should also advocate for the **prevention of institutional discrimination embedded in the configuration of the NHS, as well as the policies and laws that underlie the entitlement and enjoyment of healthcare services.** The NHS and the power relations that characterize it involves a subtle discrimination against the population that does not comply with it. Also, laws are defined in a way that the consequences are discriminatory and classist for a sector of the population that is not included within the mainstream society. In both cases, the Roma population is severely affected. Dismantling discrimination is a systems change intervention designed to change the underlying infrastructure within an institution to be more fair, just, and equitable. It seeks to demonstrate that all who seek healthcare receive equal, high quality services. The main objectives of this process should be: (a) **increasing the accountability of individuals and systems** to create a system for monitoring the elimination of healthcare disparities; (b) **reorganizing power by strengthening relationships** between organizations and community; (c) **developing a common analytic framework** for understanding why discrimination is happening in both domains; and (d) **creating opportunities for the growth and development** of all stakeholders involved in the elimination of institutional discrimination (Griffith et al., 2007).

(6) **Assuring cultural competence among stakeholders** should also guide these TRHP. According to Napier et al. (2014) "healthcare providers should acknowledge their own cultural values, and organizations should invest in understanding how their practices and values are cultural and in which extent these are adequate to the users." Being culturally competent requires learning to be effective in diverse communities-contexts that challenge the own cultural belonging (Trickett, 2009). It entails changes at cognitive level—***critical thinking***, relational level—***capacity to act***, and behavioural levels—***community embedding***: Cultural competent providers empower themselves to promote equal enjoyment of community resources, acquiring new skills, promoting changes in their organizations while instigating and advocating for the overcoming of disparities and asymmetries (Garcia-Ramirez et al., 2011). In this sense there is a need of cultural competent providers in healthcare organizations. Furthermore, it is essential for future providers to receive training in cultural competence before leaving college and university (Suurmond et al., 2013). The key is to link individual cultural competence training with organizational support, culturally sensitive practices, policy planning, and community engagement. In the same vein, a way to make healthcare services and providers more culturally sensitive would be the **institutionalization of health mediation.** TRHP should promote the creation of models of care that take seriously the importance of community health mediators (Napier et al., 2014). In addition, these mediation processes would connect the NHS with the communities, thus **promoting health literacy among users.** As emphasized by Napier

et al. (2014), “When patients lack ability, they become disproportionately incapable of participating in their own improvement, meaning that the cost of caring does not rise proportionately for those with resources, but it does rise substantially for society.” Consequently, the Roma community should be given the educational resources, information, and abilities to understand and to be empowered in order to adjust their behaviours to improve their own health and wellbeing (Napier et al., 2014).

5.2. Priorities

The principles presented above should guide the development and implementation of priorities in TRHP. The following priorities on how to tackle Roma health inequities were identified during the stakeholder interviews and meetings of the coalition:to: **Strengthening entitlement to healthcare; Assuring accessibility to the healthcare system; Promoting responsiveness in healthcare services; and Achieving and sustaining change.**

In order to **Strengthen the entitlement to healthcare** of national and foreign Roma, it is necessary (a) **to work for the defence of the right to health and to establish mechanisms and institutions to guarantee this right**, forcing laws at local, regional and national levels to comply with European directives and fundamental rights (e.g. the abolition of the RDL 16/2012); and (b) **to review the unjust administrative procedures for obtaining the Health Card** required by the Social Security System—more specifically the requirements needed for EU citizens (e.g., document provided by consulates to proof they have no health insurance in their countries of origin). These bureaucratic procedures are a **great barrier** for the most vulnerable population, especially the foreign Roma for whom obtaining the entitlement becomes almost impossible.

To **Assure accessibility to the healthcare system** through TRHP, it is necessary to go beyond good practices—that work as temporary patches—and to establish measures capable of transforming the current NHS, such as: (a) **To denounce the violation of human rights,** advocating for the defence of international laws and ensuring the implementation of superior rights. (b) **To strive against the belief that "access is equal for everyone"** or that "care is provided in equal terms", distinguishing between “equity” and “equality” and also differentiating between “access and accreditation” with “care”. (c) To **establish corrective measures or exceptional mechanisms for access** the NHS in order to reconcile situations of vulnerability and human mobility with bureaucratic requirements. (d) Other options are **to increase the health mediation processes** by **promoting networking with the community,** building trust and proximity with the most silent ranks, providing them with autonomy through knowledge about the NHS and their own health, as well as facilitating access to the NHS through other domains (e.g., education, employment, etc).

TRHP should work on the following priorities to **Promote responsiveness in healthcare services:** (a) T**o include both foreign and national Roma in plans and strategies**, and even those who due to the crisis have returned to vulnerable conditions and are unhooked of the system. In order to do so, it is crucial to have **reliable information** about the number or Roma, their location, social determinants and health inequities to effectively design policies. (b) It is also necessary **to redefine the current NHS**, which is more focused on curing and finding quick solutions to health problems than **caring for the users** and the community’s wellbeing. In this sense, the NHS needs to recover a **community health approach** that takes into account the practices and traditions of the Roma and its influence in every life domain and context (e.g. schools, neighbourhoods, workplace, etc.). (c)

From this point of view, **broader and more comprehensive health objectives from an intersectoral perspective** should be set, such as: improving child health; expanding knowledge about first aid in Roma settlements; continuing to tackle obesity and unhealthy eating in children; increasing the number of home assistance services, locating potentially excluded users and identifying specific needs; improving workplace health; promoting active aging; improving emotional health, especially in women; eliminating gender violence. (d) These goals can only be attained through the elaboration of **preventive programmes rooted in the community**—especially for chronic diseases such as diabetes and hypertension, and activities **to promote health and health literacy that are adapted to the realities**, needs and characteristics of the Roma community. These programmes must contribute in empowering the Roma population and strengthening health protective factors. (e) Moreover, the NHS should adopt other priorities to become more responsive, for example: to improve the knowledge about available resources to work with the Roma community and disseminate them among providers and users in centres with high density of Roma population; to increase the number of Roma staff in healthcare centres; to strengthen the role of Roma health mediators and Roma women as health agents in Roma communities; to develop care programs aimed at preventing burnout among providers who work with the Roma community; to promote cultural and Roma sensitive training for future and current providers; to value and disseminate examples of existing good practices and specific health programs aimed specifically at the Roma community.

Lastly, **strengthening Roma associative movement is a priority for achieving and sustaining change** through TRHP. To accomplish this is important to: (a) promote and better the communication and collaborative work among stakeholders and institutions at different levels—including sending countries; (b) promote the leadership of the Roma, (c) increase the presence of the Roma—especially foreign Roma—in associations and organizations as active citizens in the community; (d) use participatory community methodologies, resources, and networking, (e) identify valid interlocutors to work with Roma communities; (f) promote cultural exchanges among multiple stakeholders; (f) revitalize Roma organization movement by promoting new structures; and (g) foster self-criticism to reduce the fragmentation among Roma associations and prevent overprotection, tokenism and co-option. To put in practice all of the above, it is imperative to improve the viability and sustainability of the NRIS, for example, by allocating budget for the strategy, specially for its dissemination. Other measures could be to elevate the range of the commitments made by institutions towards the strategy. As a matter of fact, the Spanish NRIS is currently a Cabinet agreement that is not even published in the Official Bulletin of the State (*Boletín Oficial del Estado)*. In this sense, the NRIS could be transferred to the Parliament to acquire legal status (e.g., Organic Law, RDL), so that it could be transposed to the AACC and included in the general state and regional budgets.

5.3. Tools

The development and implementation of TRHP follows an **ecological approach**. At a community level, the tools to work for the involvement of multiple stakeholders and the development and implementation of TRHP within a specific context are the ones provided by methodologies for innovation and new technologies - more specifically, on-line platforms.

5.3.1. Methodologies for innovation

When involving multiple stakeholders by building collaborative capacity, special attention should be paid to the barriers that prevent the most vulnerable groups—especially foreign and hard-to-reach Roma—from taking part in institutional decisions (e.g., lack of information about participation opportunities, economic and time constraints, language barriers, limited self-confidence, asymmetries in power, unattractive goals, failure to accommodate cultural diversity, invalidation of users' voice, disempowering experiences).

Methodologies for innovation offer opportunities to overcome these challenges and to connect people, ideas, and resources at the same time, thus enhancing collaborative capacity. Some examples are: (a) platforms and processes for involving Roma children in in generating innovations, decision making, planning, and influencing health public policy; (b) Citizen petitions online platforms for capturing Roma's ideas on health-related issues; (c) Events and conferences for networking and learning; (d) Participatory workshops where Roma community, civil society and other stakeholders analyze, share and enhance their knowledge to plan, manage and evaluate health actions and programmes; (e) Virtual meetings, webinars, and dialogue café to link up stakeholders around the world; (f) Innovation hubs are shared work spaces designed to promote collaboration and innovation among different stakeholders working to tackle wicked problems such as Roma health; and (g) Think tanks and do tanks to generate ideas and engage them into practice in the Roma health fieldwork (Murray, Caulier-Grice & Mulgan, 2010).

These methodologies follow the **learn by doing premise,** with the following benefits: (a) developing stakeholders' skills and knowledge to work in collaboration; (b) creating positive environment and relationships among stakeholders; (c) encouraging effective leadership and communication; (d) setting realistic community-driven goals; and (e) promoting engagement and accountability in the planning, implementation, evaluation and sustainability of policies and practices (Florin et al., 2010; Foster-Fishman et al., 2001; García-Ramírez et al., 2009; Goodman, Speers & McLeroy, 1998; Fetterman, Kaftarian & Wandersman, 2004).

5.3.2. New technologies

A good way to implement TRHP is by taking advantage of **new technologies** in the field of public health. According to the EUPHA and *The Lancet*, these tools may serve not only for communities' empowerment and self-management of their own health, but also for enhancing and sustaining networking, sharing resources, knowledge, and training skills for those providers and stakeholders involved in community health with the Roma (Boyce, 2012; Zeegers et al., 2013). Box 10 provides some examples on these tools.

Box 10: New technologies in Transformative Roma Health Policies

- **Smartphones, videogames, social media, internet and mobile apps.** The *Journal of Medical Internet Research*[18] is an excellent source to find a wide range of research and actions related to web-based and mobile health interventions, e-learning, eHealth literacy, tele-health and tele-monitoring, among others. But also, to find guides for public health researchers and practitioners on how to develop these interventions (Horvath et al., 2015). Some examples about the application of these technologies in health are serious videogames aimed at preventing child and adolescent obesity (Thompson, 2014), also apps

[18] *Journal of Medical Internet Research* http://www.jmir.org/

for making healthier food choices (Dunford et al., 2014), for assessing youth sexual health programs using text messaging technology (Sheoran et al., 2014), or mobile health interventions for self-management and lifestyle change for type 2 diabetes (Holmen et al., 2014) among others.

- **Participatory mapping and Geographic Information Systems (GIS).** In fields like geography and territorial policy, participatory mapping is a well established tool since it allows improved information exchange between community members and different stakeholders in the design and implementation of actions and policies within the community (Di Gessea, 2008). Probably, the use of maps in healthcare has been mostly restricted to physiological and epidemiological studies. However, its applications can go beyond this, for example, such as a tool for empowerment. Maps can help monitor and secure access to healthcare services and resources, to facilitate their management, and to support community advocacy on health-related issues. Some examples of this are The WHO's Substance Abuse Instrument for mapping services (Babor & Pozniak, 2010), the experience on mapping mental health advocacy services in London (Foley & Platzer, 2007), or health promotion programmes using intervention mapping (Kok & Mesters, 2011). In the same vein, Geographic Information Systems are creating valuable contributions for enhancing healthcare and health information systems in the last years (Nhavoto & Gronlund, 2014).

In particular, we would like to focus on internet-based support systems such as the on-line platform "Community Tool Box,"[19] developed by the University of Kansas in the United States (Box 11). **On-line platforms** facilitates multiple stakeholders to be better prepared to work together to change health conditions that affect their lives, thus reducing the inequities that hinder the pursuit of social change and justice (Holt et al., 2013). This way, a **Roma Tool Box** could work as an **exchange network** that allows connecting multiple stakeholders at loval and globlal levels who are engaged in transforming and building healthier Roma communities. A tool like this is **a means to give voice** to local concerns and silent ranks, thus working for the empowerment of Roma users and the Roma community itself (e.g., enhancing their involvement in health service delivery design and development) (Francisco et al., 2001). It is also a great opportunity for **building capacity for systems change**, for creating and adjusting contexts **to ensure the success** of interventions, and also for **evaluating** interventions within an open system environment (Francisco et al., 2001; Holt et al., 2013). Moreover, a Roma Tool Box could be an excellent a **support infraestructure** with a wide range of resources for learning courses, training materials, workshops, assistance, access to community building skills, networking, connecting ideas, etc.

Following the recommendations of Francisco et al. (2001), the Roma Tool Box should have the following features: (a) to have a comprehensive content; (b) the information needs to be easily available on demand (e.g., readable, printable, and downloadable); (c) the information must be useful, providing step-by-step guidance to be directly applied in practice; (d) the material should be friendly and supportive for users who may lack sufficient knowledge or skills on the subject; (e) there should be exchange mechanisms to connect experts with people in need of help; (f) it should be universally available and free; and (g) it should pursue lifelong learning, being useful and helpful across generations.

[19] Community Tool Box http://ctb.ku.edu/

Box 11: The Community Tool Box

- The Community Tool Box was created in 1994 by the Work Group for Community Health and Development at University of Kansas, and collaborators (Francisco et al., 2001; Holt et al., 2013). It is a free online resource, available in different languages (i.e., English, Spanish and Arabic), widely accessed–more than a million users around the world—by multiple people, settings and organizations that seek to enhance their skills in competencies for community work. The Community Tool Box content is organized in the following way:
- *Learn a skill.* This section offers practical and step-by-step guidance in community building skills related to (a) Understanding community context (e.g., assessing community assets and needs), (b) Collaborative planning (e.g., developing a vision, mission, objectives, strategies, and action plans), (c) Developing leadership and enhancing participation (e.g., building relationships, recruiting participants), (d) Community action and intervention (e.g., designing interventions, advocacy), (e) Evaluating community initiatives (e.g., program evaluation, documentation of community and systems change), and (f) Promoting and sustaining the initiative (e.g., social marketing, obtaining grants).
- *Do the Work*. It contains toolkits with detailed how-to outlines and checklists, real world examples, training materials, etc. for different competencies (e.g., creating and maintaining coalitions, assessing community needs and resources, developing a strategic plan, developing an intervention, enhancing cultural competence, evaluating the initiative, implementing social marketing, and planning for sustainability).
- *Solve a Problem*. It offers additional support through troubleshooting guides and training courses for common dilemmas faced when starting and developing community work (e.g., planning, assessment, participation, publicity, program development, leadership, or advocacy). There is also an Ask an Advisor service by which experienced community members and experts provides brief and personalized answers to these questions.
- *Use Promising Approaches.* It provides links to comprehensive databases of evidence based practices and online resources for addressing specific community problems or goals. Community WorkStations facilitate users to easily share materials, make announcements, access tools, learn from successful community stories, and access guidance from peer discussions.
- *Connect with Others.* Besides the Ask and Advisor service, other ways to facilitate networking is through links to online resources, e-newsletters and social media.

FINAL THOUGHTS

Roma health has become an issue of global importance and awareness in Europe. However, we find ourselves in a society ruled by states that are reducing social and economic public interventions due to changes in the distribution of power and resources, which benefit some groups in detriment of others. This is reflected in new public health policies that promote (a) the transformation of NHS in privatize and insurance-based healthcare systems, (b) the reduction of public responsibility in the health of the population, (c) making individuals themselves solely responsible for their health, and (d) understanding health promotion as behavioural change (Navarro, 2013). Nevertheless, these principles are being impossible to sustain due to the current and difficult economic, social and political context, but also due to the fact that traditional responses of healthcare systems are insufficient to tackle these challenges in health. First, these systems are based in a healthcare model that aims to cure instead of caring—even when the main causes of mortality are due to diseases which cannot be cured with medical interventions (e.g., cancer, cardiovascular diseases). And second, because these systems support health prevention and promotion programs focused on individual and behavioural changes rather than structural changes, hence resulting ineffective to eliminate health inequities. Therefore, it is necessary that TRHP include political, economic, social, and cultural interventions in order to change the structural and social determinants of health. In this vein, these new public health policies should (a) encourage participation and influence in society, (b) focus on social and economic determinants, (c) carry out contextual interventions that protect users, (d) secure favourable conditions for the children, the adolescent and the elderly; and (e) create healthcare interventions that promote health. Furthermore, all these interventions should begin, in the first place, with the empowerment of Roma people as well as the rest of the civil society (Navarro, 2013).

In this endeavour, all stakeholders are called upon to play a central role in overcoming the unacceptable persecution, discrimination, and inhumane life that Roma people suffer in opulent Europe. The difficult circumstances in which many Roma live drives us to develop creative TRHP and initiatives while trying to reduce their suffering, which is an urgent matter. How can we walk this fine line without our work being allied with the dominant structures that uphold existing inequities and perpetuate discrimination and prejudice? First, our task is to erase the “social inequalities kill” misconception by bringing up the issue of power, thus pointing out that those who kill are responsible for and the ones who benefit from the inequalities that kill (Navarro, 2013). And second, we are obliged to help Roma communities to live day by day, to strengthen their critical thinking, and to build expectations of prosperity among people whose situation prevents them from recognizing their own potential for liberation and happiness. These can be overwhelming tasks. However, both endeavours are an example of how stakeholders are committed in the pursuit of meaning for Roma people and their communities (Prilleltensky, 2014). With this overall objective in mind, this paper hopes to provide a valuable and critical example of the complexity of overcoming inequities in well-being and health, by balancing transformative and ameliorative purposes in policies from a stakeholder perspective when conditions of inequality seriously jeopardize the health and well-being of voiceless groups.

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ANNEX I. DESK REVIEW

- **Cabedo García, V.R., et al. (2000). Cómo son y de qué padecen los gitanos. *Atención Primaria, 26*(1).** This study is of interest as it compares national Roma and non-Roma according to their socio-demographic characteristics and health status. The results showed more social and health risks and higher incidence of some diseases in Roma. They also showed an early average age of death, labor situation and education level more unfavorable than non-Roma. The fact that Roma use more the private healthcare was also found.
  Correspondence with analytical framework: Social determinants and health.

- **Consejería de Salud y Bienestar Social, Junta de Andalucía (2012). *Instrucciones de la DG de Asistencia Sanitaria y Resultados en Salud del Servicio Andaluz de Salud sobre el reconocimiento del derecho a la asistencia sanitaria en centros del Sistema Sanitario Público de Andalucía a personas extranjeras en situación irregular y sin recursos.*** This document is response to the Royal Decree-Law 16/2012. This instruction recognizes the right to healthcare for undocumented foreigners without resources in centers of the Public Health Service of Andalusia.
  Correspondence with analytical framework: Coherence with EU Communications and Council Conclusions; Health system strengthening; Goals, outcomes and governances mechanisms.

- **Consejería de Trabajo y Asuntos Sociales, Junta de Andalucía (1996). Plan Integral Comunidad Gitana de Andalucía.** This plan seeks the promotion of Roma with special social problems in different areas (housing, education, training and employment, health, culture, social action and woman) such as: (1) to carry out action strategies aimed to Roma's promotion, prevention, treatment and elimination of marginalization; (2) to coordinate and make profitable the existent resources and set up new ones in order to improve the quality of the attention of the Roma community; (3) to promote the participation and action of this community in issues that affect their development; (4) to provide sensitivity to public opinion; and (5) to promote the knowledge of Roma on public systems of social protection and normalize its use.
  Correspondence with analytical framework: Coherence with EU Communications and Council Conclusions; Health system strengthening; Goals, outcomes and governances mechanisms; Monitoring and evaluation.

- **Cortes Generales de España (1978). Constitución Española.** The Spanish Constitution is the supreme law of the Kingdom of Spain and it includes the most basic rights—including health—that must be applied to every citizen.
  Correspondence with analytical framework: Coherence with EU Communications and Council Conclusions; Health system strengthening; Goals, outcomes and governances mechanisms.

- **Departament de Benestar Social i Família, Generalitat de Catalunya (2006, 2009). I and II *Pla Integral del Poble Gitano a Catalunya 2005-2008*. Departament de Benestar i Família.** Both plans aim to combat, from a global perspective, the inequality suffered by the Roma population in Catalonia as well as promote and recognize the cultural features that are unique to this group. For that, they have action plans for different areas: culture and

identity, family, housing and urban development, education, employment, health and sanitation, social participation, language, media and social image, justice and public safety.
Correspondence with analytical framework: Coherence with EU Communications and Council Conclusions*;* Health system strengthening; Goals, outcomes and governances mechanisms; Monitoring and evaluation.

- **Departament de Salut, Generalitat de Catalunya (2006).** ***Pla Director d'Immigració en l'Àmbit de la Salut*****. Departament de Salut.** This plan targets improving the health of the immigrant population by defining a model of attention and service reorganization of the Catalan health system. Its objectives focus on maternal and child health, HIV, sexually transmitted diseases, tuberculosis and cancer.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions*;* Health system strengthening; Goals, outcomes and governances mechanisms; Monitoring and evaluation.

- **Departament de Salut, Generalitat de Catalunya (2012).** ***Instrucció 10/2012. Accés a l'assistència sanitària de cobertura pública del CatSalut als ciutadans estrangers empadronats a Catalunya que no tenen la condició d'assegurats o beneficiaris del Sistema Nacional de Salut.*** This instruction discusses access to the public healthcare system of Catalonia for registered foreigners without legal residence and not recognized by the NHS. This document is the regional response to the Royal Decree-Law 16/2012.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Health system strengthening; Goals, outcomes and governances mechanisms.

- **Family Voices (2009). Growing Your Capacity to Engage Diverse Communities by working with Community Liaisons Cultural Brokers.** This report offers an overview of the work developed by cultural brokers and community liaisons, as well as it provides tools to make informed decisions, advocate for improved public and private policies, build partnerships among families and providers and serve as a trusted resource on healthcare.
Correspondence with analytical framework: Health system strengthening.

- **Ferrer, F. (2003). El estado de salud del pueblo gitano en España. Una revisión de la bibliografía.** ***Gaceta Sanitaria, 17(Supl 3):2-8****.* This article discusses which Roma health-related issues had received attention in the literature, and whether their ethnic differences and social inequalities had been studied. The results show that most frequent topics were genetics or congenital anomalies, transmissible diseases, child health, and health sociology. They also show that 57% of the studies reported some social inequalities in health.
Correspondence with analytical framework: Social determinants and health.

- **Fundación Secretariado Gitano (2006). Handbook for Action in the Area of Health Services with the Roma Community.** This Handbook is of interest because it was compiled as a contribution to the reduction of health inequalities in the NHS. Its goal is to achieve equally and culturally adapted treatment for users and their needs. To that end, the Handbook lays down a series of action proposals designed to correct inequalities regarding the access of Roma to the public health system.

Correspondence with analytical framework: Coherence with EU Communications and Council Conclusions; Social determinants and health; Health system strengthening; Goals, outcomes and governances mechanisms; Monitoring and evaluation.

- **Fundación Secretariado Gitano (2012). Políticas De Inclusión Social Y Población Gitana En España. Editorial Dobrogea, FSG.** This report consists of review and assessment of the past and current policies and factors that have contributed—and hindered—the social inclusion of Roma population in Spain.
  Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Health system strengthening; Goals, outcomes and governances mechanisms; Monitoring and evaluation.

- **Fundación Secretariado Gitano (2013). El impacto de la crisis en la comunidad gitana. Madrid: Autor.** In this document is described the impact that the economic crisis and austerity measures have on the Roma community in Spain, including the area of health. It is found that the crisis affects more the groups who were already vulnerable, causing decline or stagnation in the progress made by the Roma community in recent decades.
  Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; Monitoring and evaluation.

- **Ley 14/1986, de 25 de abril, General de Sanidad.** This Law establishes the general regulations of the healthcare services in Spain. Also, it contemplates all its actions that afford to implement the right to health protection, being holders of this right all Spanish and foreign citizens who have established their residence in the country.
  Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Health system strengthening; Goals, outcomes and governances mechanisms.

- **Ley Orgánica 15/1999, de 13 de diciembre, de Protección de Datos de Carácter Personal.** This Organic Law aims to guarantee and protect the processing of personal data, civil liberties and fundamental rights of physical persons, and especially their honor and personal and family privacy. It is relevant to our study as it contemplates the protection of ethnic data, this having consequences for Roma policies and strategies.
  Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Goals, outcomes and governances mechanisms.

- **Ley 16/2003, de 28 de mayo, de cohesión y calidad del Sistema Nacional de Salud.** The object of this Law is to establish the legal framework for coordination and cooperation actions of the public health authorities in the exercise of their respective powers, so that equity, quality and social participation in the NHS is guaranteed, as well as the active participation of the latter in reducing health inequalities.
  Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Health system strengthening; Goals, outcomes and governances mechanisms.

- **Real Decreto-Ley 16/2012, de 20 de abril, de medidas urgentes para garantizar la sostenibilidad del Sistema Nacional de Salud y mejorar la calidad y seguridad de sus prestaciones.** This document represents an important milestone in shaping the Spanish healthcare system. Until 2012, the NHS was aimed at universality. Since the entry into force

of this Royal Decree-Law (RDL), the beneficiary status of the NHS changed into insured of the Social Security system, thus limiting the right and access to healthcare for those who are not considered as such.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Health system strengthening; Goals, outcomes and governances mechanisms.

- **La Parra, D. (2009). Hacia la equidad en salud: Estudio comparativo de las encuestas nacionales de salud a población gitana y población general de España, 2006. Ministerio de Sanidad y Fundación Secretariado Gitano.** This is a comparative study of the National Health Surveys of 2006 to Roma and non-Roma population of Spain. We consider it interesting, as it is the first study done in Spain describing the impact of social determinants on Roma health in order to detect possible health inequalities affecting this community in comparison with the general population. Lifestyle and access to healthcare services are issues that affect in a negative way the Roma community´s health.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; System strengthening; Monitoring and evaluation.

- **La Parra, D., Gil-González, D., & Jiménez, A. (2013). Los procesos de exclusión social y la salud del pueblo gitano en España. *Gaceta Sanitaria, 27*(5), 385-386.** This article presents a review of the Roma health and social situation in Spain. It provides information on both topics and analyses the main EU programs implemented in recent years for this population and the plans carried out in Spain in line with the EU. It also offers recommendations for actions to advance social equity and better health of Roma in Spain.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; Monitoring and evaluation

- **Laparra, M. (ed.) (2011). Diagnóstico social de la comunidad gitana en España. Un análisis contrastado de la Encuesta del CIS a Hogares de Población Gitana 2007. Madrid: Autor.** This report is interesting due to the data and information provided on the Roma community, its structure, population size, and data about their health status and social factors that influence it.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; Monitoring and evaluation

- **Laparra, M. (Ed.) (2007). Situación social y tendencias de cambio en la Comunidad Gitana. Ministerio de Sanidad**. This report reviews the research and studies on Roma community that had been carried out in Spain during the last decades. It is of interest because it provides information about Roma population and demographic structure, as well as issues regarding their health, analyzing the relationship of this community with the healthcare system and its healthcare models.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; Monitoring and evaluation

- **Laparra, M., et al (2012). Civil Society Monitoring Report on the Implementation of the National Roma Integration Strategy and Decade Action Plan in 2012 in Spain. Budapest: Decade of Roma Inclusion Secretariat Foundation.** This is a monitoring report on the NRIS

actions developed in Spain until 2012. It presents alternative information to the assessment made by the government, describing the results obtained in several areas. Regarding health, it provides data on the Roma health status and its factors, stressing the consequences of the economic crisis such as the deterioration of the public health services.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; System strengthening; Monitoring and evaluation.

- **López Catalán, O. (2012). Visión General de la Población Rrom/Gitana Rumana.** The aim of this document is to provide an overview of foreign Roma in Spain, thus being of interest to this report. It offers a coherent and basic framework to understand some of the specificities regarding this population. Among others, information about their relationship with healthcare services and their difficulties encountered to access and enjoy them.
Correspondence with analytical framework: Social determinants and health.

- **Mendez, C. (2007). Desigualtats socioeconòmiques i diferència cultural a l'àmbit de la salut en barris d'actuació prioritària de Catalunya.** This document talks about inequalities in health and access to healthcare services through the prism of cultural differences and diversity within the Roma community. It also provides some suggestions for action to improve the health status of this group.
Correspondence with analytical framework: Social determinants and health; Health system strengthening.

- **Ministerio de Educación, Política Social y Deporte (2008). National Action Plan on Social Inclusion of the Kingdom of Spain 2008-2010.** This document represents the development of national plan aimed for people who are at risk of social exclusion. The priority objectives are fostering access to employment, guaranteeing minimum economic resources, achieving an equitable and quality education system, supporting the social integration of immigrants and guaranteeing equality in assistance to persons in a situation of dependence. It includes also actions aimed at the Roma community.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Health system strengthening; Goals, outcomes and governances mechanisms; Monitoring and evaluation

- **Ministerio de Sanidad y Consumo & Fundación Secretariado Gitano (2007). Health and the Roma Community. Analysis of action proposals. Madrid: Ministerio de Sanidad y Consumo.** This document provides an initial diagnosis of the health status of national Roma in Spain in order to identify their principal needs and thus contribute to the elimination of the existing health inequalities faced by this group. It describes the main weaknesses, threats, strengths and opportunities of the Roma community related to health and it also provides recommendation for actions.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; Monitoring and evaluation

- **Ministerio de Sanidad, Política Social e Igualdad (2010, 2012). Progress report 2010 and 2012 on the NRIS in Spain.** These reports provide information on the implementation of the NRIS in Spain in 2010 and 2012 as well as data on the Roma and the programs and actions

carried out in Spain within the action plan of the Decade of Roma Inclusion during those years.
Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; System strengthening; Monitoring and evaluation.

- **Ministerio de Sanidad, Política Social e Igualdad (2011). Action Plan for the Development of the Romani population 2010- 2012.** This plan is relevant, as it was developed to promote new actions to correct the existing imbalances between the Roma and the rest of the Spanish population. In order to achieve this, it highlighted the need of encouraging different forms of participation and social development that ensure Roma full exercise of social rights and access to goods and services; improving their image and promoting equal treatment; and contributing to the promotion of the European policy in favor of the Roma and its participation in the development.
  Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; Health system strengthening; Goals, outcomes and governances mechanisms; Monitoring and evaluation

- **Ministerio de Sanidad, Política Social e Igualdad (2012b). National Roma Integration Strategy in Spain 2012 -2020.** This is the core document on which the national consultants have relied on to develop this progress report on the implementation of the NRIS in Spain. This strategy was conceived as European opportunity to strengthen and heighten the channels and measures aimed at integrating the Roma in different areas of our societies (these are education, housing, employment and health).
  Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; System strengthening; Goals, outcomes and governances mechanisms; Monitoring and evaluation.

- **Ministerio de Sanidad, Política Social e Igualdad (2012c). Guía metodológica para integrar la Equidad en las Estrategias, Programas y Actividades de Salud.** This methodological guide aims to raise awareness among health providers, policymakers and other sectors whose policies have an impact on health and social determinants. It provides a practical tool to facilitate the effective integration of equity in health strategies, programs and activities.
  Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; System strengthening; Goals, outcomes and governances mechanisms; Monitoring and evaluation.

- **Ministerio de Sanidad, Política Social e Igualdad (2013). Plan Operativo 2014-2016 de la NRIS.** This is the first Operational Plan that supports the implementation of the NRIS in Spain. Following the guidelines of the EU, it establishes measurable objectives and facilitates strategies in the areas of education, employment, housing and health to achieve in the timeframe of 2020. In this document some activities are already proposed for 2014. These activities can be specific for the Roma or for the general population.
  Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; System strengthening; Goals, outcomes and governances mechanisms; Monitoring and evaluation.

- **Ministerio de Sanidad, Política Social e Igualdad (2013b). Real Decreto 576/2013, de 26 de julio, por el que se establecen los requisitos básicos del convenio especial de prestación de asistencia sanitaria a personas que no tengan la condición de aseguradas ni de beneficiarias del Sistema Nacional de Salud y se modifica el Real Decreto 1192/2012, de 3 de agosto, por el que se regula la condición de asegurado y de beneficiario a efectos de la asistencia sanitaria en España, con cargo a fondos públicos, a través del Sistema Nacional de Salud.** This document states another milestone in the configuration of the NHS in Spain. After the RDL 16/2012, this decree represents the transformation of the NHS—previously universal and funded by the State—in a sort of private health insurance company through which those excluded from the healthcare system can access by paying a monthly fee.
  Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Health system strengthening; Goals, outcomes and governances mechanisms.

- **Sánchez Serrano, F.J., et al. (2002). Diferencia étnica en la actividad asistencial de urgencias. Aproximación a la realidad gitana. *An Esp Pediatr, 56*, 17-22.** The study shed light on the situation of Roma children. This article aims to determine the health, social and welfare characteristics of Roma children in comparison to the rest of the population.
  Correspondence with analytical framework: Social determinants and health; Health system strengthening.

- **Slavkova, M. (2010). Estrategias migratorias de la población gitana búlgara en España. *Revista de Recerca i Formació en Antropologia, 12.*** This paper is relevant to know about foreign Roma in Spain coming from Bulgaria. It presents the reasons and characteristics of migration flows of Bulgarian Roma, as well as it provides information about their access to healthcare services and the strategies and difficulties in this area.
  Correspondence with analytical framework: Social determinants and health.

- **World Health Organization and Ministerio de Sanidad y Consumo (2008). *Promoción de la salud. Glosario*. World Health Organization, Ginebra.** The basic purpose of the glossary is to facilitate health communication between countries and within them, as well as between the different organizations and individuals working in this field. It provides an agreed definition on health within European framework.
  Correspondence with analytical framework: Coherence with EU communications and Council conclusions; Social determinants and health; Health system strengthening.

ANNEX II. EQUI-HEALTH STAKEHOLDERS IN SPANISH COALITION

Policymakers and healthcare organizations

- **Direcció General (DG) per a l´Immigració (DGI – Dept. Benestar Social i Família, Generalitat de Catalunya):** They propose policies for the integration of immigrants, which are then considered by the Catalonian government. They also coordinate the actions of the different departments and local organizations working in this field. They have developed social cohesion programmes in areas with a high Roma population density from Eastern Europe. Finally, they have constituted a technical team to coordinate the assistance of immigrant Roma population in all policy areas. For more information: http://www.gencat.cat/benestarsocialifamilia/immigracio

- **D.G. d´Atenció a la Infància y l´Adolescència (DGAIA - Dept. Benestar Social i Família, Generalitat de Catalunya):** This institutional body has collaborated with the Catalonian Fundación Secretariado Gitano in the social inclusion programme for Roma coming from Eastern Europe. Some of its main activities within this programme included social and medical care support and accompaniment, promotion of family health, schooling support and school reinforcement. For more information: http://www20.gencat.cat/portal/site/bsf/menuitem.7fca6ecb84d307b43f6c8910b0c0e1a0/?vgnextoid=4e0622a30e5a4210VgnVCM1000008d0c1e0aRCRD&&

- **D.G. d'Acció Cívica i Comunitària (Dept. Benestar Social i Família, Generalitat de Catalunya):** This institution has chaired the Inter-departmental Commission of the Comprehensive Plan of the Roma population, whose committee is composed of representatives from the different departments in the Catalonian government. They put forward measures to coordinate and monitor interdepartmental actions within the Plan Integral. For more information: http://www20.gencat.cat/portal/site/bsf/menuitem.cb7c44c1c72cf6b43f6c8910b0c0e1a0/?vgnextoid=81c2e5f0edf6d210VgnVCM2000009b0c1e0aRCRD&vgnextchannel=81c2e5f0edf6d210VgnVCM2000009b0c1e0aRCRD&vgnextfmt=default

- **Direcció d'Atenció al Ciutadà. Regió Sanitària Barcelona (Generalitat de Catalunya**): They provide Health Cards for citizens and process and monitor users' access to the NHS, being in charge of monitoring waiting lists and accessibility. They also assess user assistance, manage complaints and claims, and process cost recovery, benefits applications and support services. For more information: http://www14.gencat.cat/sacgencat/AppJava/organisme_fitxa.jsp?codi=7001

- **Agència de Salut Pública de Catalunya (ASPCAT – Secretaria General de Salud Pública del Departamento de Salud- Generalitat de Cataluña**): The main aim of this agency is to protect citizens' health and safety through prevention, promotion and protection health programmes. They also offer troubleshooting services in public health. Their work is based on cross-sectoral collaboration and shared responsibility among different agents. Regarding their specific role with Roma population, ASPCAT has promoted the development of health

policies adapted to the needs of the Roma community, for example, by implementing programmes that improve the accessibility and quality of health services, training programmes for healthcare providers, and mediation programmes. For more information: http://www20.gencat.cat/portal/site/salut/menuitem.81a4919118f3026913a90f10b0c0e1a0/?vgnextoid=afc125837e73f310VgnVCM2000009b0c1e0aRCRD&vgnextchannel=afc125837e73f310VgnVCM2000009b0c1e0aRCRD&vgnextfmt=default

- **Centro de Atención Primaria Santa Rosa (Institut Catalá de la Salut, Generalitat de Catalunya):** This PHC center is in Santa Coloma de Gramanet, a city in the province of Barcelona with nearly 40 per cent of immigrant population, mostly from Eastern Europe. This centre carries out important community health actions addressed to foreign Roma, including assistance to excluded users, health promotion and childhood health projects, among others. For more information: http://www14.gencat.cat/sacgencat/AppJava/organisme_fitxa.jsp?codi=7978

- **Hospital del Mar (Institut Catalá de la Salut, Generalitat de Catalunya):** This is the main healthcare service in Parc de Salut Mar, on the coast of Barcelona. It is a community hospital very much involved in primary care that has become a model for nearby districts such as Ciutat Vella and Sant Martí. This hospital assists large numbers of national and foreign Roma patients and it has implemented mediation programmes for this population. For more information: http://www.parcdesalutmar.cat/hospitals/hospital-del-mar/

- **Hospital Universitari Germans Trias i Pujol (Institut Catalá de la Salut, Generalitat de Catalunya):** This is the most important health centre in the Northern Metropolitan area of Barcelona and it is on the Can Ruti campus in Badalona. It assists a large national and foreign Roma population. Some of the Roma immigrants it assists are undocumented, which means that the hospital has to work closely with Non-Governmental Organizations (NGOS) so that this population can access social and health services. For more information: http://www.gencat.cat/ics/germanstrias/

- **D.G. de Coordinación de Políticas Migratorias (Junta de Andalucía):** This body is in charge of promoting, coordinating and assessing the public health policies of the different offices in the Andalusian regional government. It also liaises with other public administrations and citizens in order to adequately implement these policies. Finally, it encourages intercultural tolerance and respect for diversity in Andalusia. Furthermore, it has subsidised programmes specifically addressed to the Eastern European Roma population in Andalusia up until 2009, when this population became part of the EU. For more information: http://www.juntadeandalucia.es/organismos/justiciaeinterior/consejeria/dgcpm.html

- **Secretaría para la Comunidad Gitana (D.G. de Servicios Sociales e inclusión, Junta de Andalucía):** It is in charge of advising and coordinating actions to provide comprehensive assistance to Roma people. It also elaborates, implements and assesses the Plan Integral para la Comunidad Gitana in Andalusia, as well as the actions of the Plan Nacional de Desarrollo Gitano that apply to the region. Among other activities, it has created and runs the Centro Sociocultural Gitano Andaluz. For more information:

http://www.juntadeandalucia.es/organismos/igualdadsaludypoliticassociales/areas/inclusion/comunidad-gitana/paginas/secretaria-comunidad-gitana.html

- **Centro de Atención Primaria Polígono Sur (Servicio Andaluz de Salud, Junta de Andalucía):** This PHC centre is located in Polígono Sur, one of the most depressed and marginalised areas in Seville with a large national Roma population and other vulnerable groups. This centre is important for its work in the promotion of reproductive and sexual health among Roma women through a successful family planning programme, which is the case study used in this report.

Academia

- **Grupo de Recerca en Antropologia Fonamental i Orientada (GRAFO, Universitat Autònoma de Barcelona):** This group develops research and actions for socio-cultural transformation. It focuses on the study of the Roma community, its cultural representations and customs, its presence in institutional contexts, as well as processes of social integration, social relations and associationism. For more information: www.grafo.cat

- **Coalition for the Study of Health, Power and Diversity (CESPYD – Universidad de Sevilla):** This interdisciplinary research group develops research on and actions with intercultural and vulnerable groups, especially in relation to healthcare and social action. Its main aim is to empower communities and social agents to get involved in processes of social change. This is done through interventions that take into consideration these groups' needs and strengths. For more information: www.cespyd.es

Community

- **Federació d'Associacions Gitanes de Catalunya (FAGIC):** This is a nonprofit organisation that brings together all the Roma associations in Catalonia. Its main aim is to defend and promote Roma rights and culture. It also mediates with the public administration in order to optimise resources and adapt its actions to the needs of the Roma population. Among other activities, it offers advice, support, troubleshooting and mediation services in healthcare. It also organises training courses for healthcare providers in order to ensure the quality of healthcare services. For more information: www.fagic.org

- **VINCLE. Serveis a la persona i a la Comunitat. Associació per la recerca i l'acció social**: This is an institutional body devoted to promoting positive changes in society. It intends to raise social awareness, to increase social involvement and to empower vulnerable groups in order to ensure their social integration. Collaborative work between public institutions and citizens allows them to develop community actions that encourage social participation and the integration and support of socially excluded groups such as the foreign Roma. For more information: www.vincle.org

- **Fundación Secretariado Gitano (Cataluña y Andalucía):** This is an intercultural, nonprofit social organisation that promotes the development of the Roma community. To do so, it works towards achieving full citizenship for the Roma population, promoting their access to rights, services, goods and social resources, improving their social conditions, fostering

equality, and valorising Roma culture and identity. In the field of healthcare, it elaborates national and international reports on the health of the Roma people. It also collaborates regionally and locally by providing technical assistance to public and private health centres and by organising cultural training courses for healthcare providers. For more information: http://www.gitanos.org/

- **Federación de Mujeres Gitanas (FAKALI) y Asociación de Mujeres Universitarias Romí Andaluzas (AMURADI):** FAKALI is an organisation that comprises several associations of Roma women in Andalusia, including AMURADI. Both seek to promote associative actions among young Roma women as agents of social change; to provide the public administration with the necessary tools to facilitate the implementation of policies that are sensitive to Roma women; to promote gender and ethnic equality; and to make the Roma culture and heritage known to society. For more information: http://www.amuradi.org/

- **Unión Romaní Andalucía:** This is an NGO created and directed by Roma people. It works towards the recognition of their culture as a positive contribution to society, both nationally and internationally. Some of its activities in healthcare include intercultural mediation and the training of mediators and healthcare providers and support to health centres in assisting the Roma community. They also offer support for health centres assisting Roma patients; transportation and accompaniment to health centres for families; and health education for communities excluded in settlements. For more information: www.unionromani.org

ANNEX III. SPANISH GUIDELINE FOR STAKEHOLDERS INTERVIEW

- ¿Cuáles son las principales barreras en el acceso a los servicios de salud primarios, de emergencia y especializados para los gitanos nacionales, Romaníes europeos y de terceros países?
- ¿Cuál es la cobertura actual de salud de estos grupos? ¿Qué soluciones existen a nivel local para aquellos con baja cobertura?
- ¿Conoce la National Roma Integration Strategy?
    - ¿Sabe cómo se está implementando? ¿Y financiando?
    - ¿Sabe cuáles son los mecanismos de evaluación y monitorización?
    - ¿Cómo participan las autoridades regionales, locales y nacionales en esta estrategia?
- La NRIS pretende mejorar:
    - En población adulta, la percepción de salud, reducir los accidentes de tráfico, el consumo de tabaco en hombres, la obesidad en mujeres así como el número de éstas que nunca han acudido al ginecólogo. ¿Conoce intervenciones encaminadas a conseguir estos objetivos?
    - En menores, los objetivos son reducir el número de accidentes domésticos, la obesidad infantil y mejorar la salud dental. ¿Conoce intervenciones encaminadas a conseguir estos objetivos?
- ¿Se incluyen objetivos específicos para reducir la desigualdad y la atención a la diversidad en los servicios del Sistema Nacional de Salud?
- ¿Se adaptan culturalmente los recursos y servicios del SNS cuando es necesario?
- ¿Conoce políticas y acciones dirigidas a reducir las desigualdades de salud en niños, adolescentes y mujeres?
- ¿Se reorientan los servicios de salud hacia la igualdad en áreas de promoción, prevención y la asistencia sanitaria?
- ¿Se llevan a cabo medidas activas de promoción de la salud en niños y adolescentes Romaníes? ¿Sabe si los servicios de pediatría proveen información y promueven formación para la población Romaní?
- ¿Existen mecanismos que aseguren un impacto en la salud de la población Romaní en las estrategias y planes propuestos por el Ministerio de Sanidad y por las Comunidades Autónomas?
- ¿Se fomenta el trabajo transversal y la coordinación con otras entidades, instituciones y planes?
- ¿Se fomenta la colaboración y la participación de la comunidad Romaní?
- ¿Se apoyan e impulsan actividades de formación para proveedores sanitarios en diversidad, capacidades interculturales e igualdad?
- ¿Conoce algún programa sobre mediadores en salud con población Romaní?
- ¿Podría decirnos alguna buena práctica con un enfoque integral de la asistencia sanitaria a población Romaní a nivel nacional/regional/local? ¿Y lecciones aprendidas?
- ¿Sabe cómo las estrategias y acciones nacionales/regionales contribuyen o se relacionan con las estrategias sobre desigualdades en salud de la Comisión Europea (e.g. Europa 2020, Health 2020, EC: Solidarity in health, etc.)?
- ¿Conoce otros programas de salud a nivel nacional o regional relevantes para la población Romaní financiados por la Comisión Europea (e.g. en educación, empleo)?
- Recomendaciones/sugerencias para planificar futuras políticas y planes en salud para los Roma.

ANNEX IV. TERMS OF REFERENCE OF THE EQUI-HEALTH PROJECT

Terms of Reference
National Consultant [country]

Title of contract

Progress report from a multi-stakeholder perspective on the implementation of the NRIS (National Roma Integration Strategy) and other national commitements in respect to Roma Health in **[country]**

Project background and purpose of contract

In February 2013, the International Organization for Migration launched the Equi-Health project: *Fostering health provision for migrants, the Roma, and other vulnerable groups* aimed at improving the access and quality of health care services, health promotion and prevention to address health inequities in the EU. The Equi-Health is a direct grant awarded to IOM by the EC DG Health and Consumers, within the Public Health Programme 2012.

The sub-action on Roma Health has for an objective strengthening of national, regional, and EU level approaches to Roma. To this end, it will develop a coherent network and promote dialogue among key stakeholders on Roma health related issues and delineate strategies and interventions to support capacity building and cooperation within and between participating states. As part of the activities, progress country reports on national integration strategies for Roma health, as well as case studies on good practices and recommendations for better use of structural/cohesion funds for health and vulnerable groups are planned to support EU Member States to better monitor, share and strengthen their national approaches to Roma health.

Planned participating countries include EU countries with high percentage of Roma nationals and committed/interested EU countries with high percentage of Roma migrants.

These Terms of Reference (ToR) outline the details of the assignment to be carried out by the Consultant on assessing the actions taken to date in respect to health, including the implementation of national programmes and promising practices as well as lessons learnt from unsuccessful/poor practices in selected countries. The analysis will focus on the implementation of the Roma Integration strategies, as well as national action plans and commitments as to improving Roma health.

Scope of work to be performed by the Consultant

The Consultant's task shall include drafting of a **progress report from a multi-stakeholder perspective** on the implementation of the NRIS (National Roma Integration Strategy) and other national commitements in respect to Roma Health in [country]. This report will be considered as a baseline report to cover national developments since 2005 to 2013 in the field

of Roma health policy interventions. It will be followed by a second report to assess the progress made in comparison to the baseline situation in 2015.

The work will require both desk and fieldwork research. The purpose of the desk research will be to contextualize and provide the background for the fieldwork research consisting of interviews with stakeholders and a case study to form the final progress report.

The research should cover the following areas:
- Legal and policy developments in respect to Roma health national programmes and action plans with special focus on the NRIS (process of development, objectives, planning and implementation on both national and local levels and in respect to relevant recommendations incl. both binding and non-binding documents, issued by the EU bodies)
- Mapping of promising practices as well as lessons learnt from unsuccessful/poor practices (a possibility for such is suggested in the form of a case study/ies) on both national and local/community levels

Target group(s)

Health, social inclusion and other national authorities of EU Member States (MS) directly and/or indirectly involved in the provision of and access to healthcare services to Roma communities.

The final beneficiaries of the project are European Roma communities being national citizens and/or migrants within the EU.

Glossary of terms

The Equi-Health glossary of Roma and Travellers is following the terminology used by the Council of Europe (CoE).[1]

In addition, the following terms will be used:

- Roma nationals, referring to citizens of EU MS from Roma ethnic origin;
- Roma migrants referring to migrants, EU citizens from Roma ethnic origin (in the sense of EU internal migration/ mobility), and;
- Roma TCN (third country nationals), referring to migrants from third countries to the EU from Roma ethnic origin (for example migrants to the EU from the Western Balkans).

[1] See CoE's (2006) *Glossary on Roma and Travellers*: http://www.coe.int/t/dg3/romatravellers/default_en.asp

Specific activities

Activity 1: Desk research

1. The desk research will provide an overview of existing studies and data from 2005 onwards (with an indicative start of the Roma Decade) on the Roma health situation in the country, as well as a review of any national programmes and developments relevant to the topic of Roma health.

2. The desk review should consists of:
   a) *Literature review* to revise available data and information on Roma population (national and/or migrants) in terms of numbers, health status and access, quality of health with special focus on basic, emergency and specialized health care services, as well as women and children health (*Please see content of progress report*).
      - **Sources:** Published peer-reviewed literature (journals, online health databases); reports from governmental and non-governmental agencies as well as intergovernmental and UN agencies; bibliographies of recent EC/FRA publications and other major references; databases on ethnicity and health; relevant internet sites/databases of good practices such as that of OSI, Roma Decade, CoE, etc.

   b) *Legal review* to outline the legal provisions in terms of access to health care services for Roma population (national and/or migrants) in the country, discrimination, right to health and existence of complaint mechanisms in case of discrimination in access to health with special focus on basic, emergency and specialized health care services, as well as women and children health.
      - **Sources:** Identification/collection and analysis of legislation incl. local resources, and documents at national, regional/provincial, and community levels.

   c) *Policy research* to review barriers in access to health services (e.g. geographic, economic, etc.) experienced by Roma population (national and/or migrants) and how these barriers are tackled by the national polices and strategies incl. the NRIS, analysis of "good"/ promising practices as well as lessons learnt from unsuccessful/poor practices with special focus on basic, emergency and specialized health care services, as well as women and children health.
      - **Sources:** EU and national statistics on health, academic research, NGO reports and other sources, health authorities' documents and websites in English, as well as national languages.

3. Taking into account the challenges in data collection, the Consultant should aim to identify and combine information from various sources in order to obtain the most comprehensive country overview. If any specific data is not available, the Consultant should indicate the respective data gaps in the report.

4. IOM will provide a list of sources available in English to be thoroughly considered during the desk research phase as a starting point of the analysis *(see annex I).*

5. The Consultant is responsible for the analysis of additional information from sources available in the national language and the collection of additional data locally.

Activity 2: Development of questionnaires for stakeholder interviews

1. On the basis of the findings from the desk research *(on topics of major concern, identified gaps, where insufficient information for valid research conclusions, and/or evidence on promising/poor practices)* the Consultant shall draft (a) questionnaire(s), in close coordination with IOM, for semi-structured interviews to be used during the fieldwork with varied groups of stakeholders, relevant to the topic of research.

2. The Consultant shall provide a list of topics he/she would suggest to further investigate in respect to NRIS national commitment' implementation and other programs of relevance. The following issues should be considered in the questionnaire(s) as minimum:

   - Barriers in access to basic, emergency and specialized health care services for Roma
   - Social security coverage and existing local solutions to low security coverage amongst Roma communities *(if such exist)*
   - National context:
     - NRIS (health strand): process of development (and revision), national commitments' implementation, evaluation/ monitoring mechanisms, funding & sustainability, involvement of local authorities and CSO.
     - Other national (health) programmes relevant to the issue of Roma health (i.e. EC funded programmes in the field of regional development, education, employment, etc.)
   - EU context: how national strategies (and actions) relate to and contribute to the EC policies on health inequalities, with particular attention to the Europe 2020 Strategy for smart, sustainable and inclusive growth, COM(2009) Solidarity in Health: Reducing health inequalities in the EU, the EU cohesion policy and other EU strategic documents *(as per references provided in annex)*
   - Roma Health Mediators Programme(s) (implementation, challenges, monitoring mechanisms, evaluation, sustainability and institutionalization).
   - Collection of disaggregated data to support evidence based polices at national/ local level.
   - Examples (promising initiatives and/or lessons learnt from unsuccessful ones), practices of integrated approach to healthcare at national/ local level.

Activity 3: Key stakeholder interviews

1. The Consultant should suggest and then conduct an agreed number of semi-structured interviews with the objective to generate a multi-stakeholder perspective on the situation in the country.

2. The respondents will include representatives of national/regional and local authorities in selected municipalities, CSOs and experts working in the field of Roma health, as well as Roma in order to account from a multi-stakeholder perspective on the challenges faced by the Roma population in access to health and identify existing policy solutions and their

implementation in response to these challenges in the context of NRIS and other national programs.

Activity 4: Case study

1. On the basis of the desk research and key stakeholder interviews, the Consultant should propose a topic for a case study to focus more in details on specific problem of interest for the analysis.

2. The topic can be any of the previously mentioned issues of concern and/or a new problem or initiative, as far as its relevance to the national context is well argumented and coordinated with IOM.

Activity 5: Analysis and presentation of results

1. Presentation of preliminary results at NCC (National Consultative Committee) Meeting in the country (organized by IOM country office)

   - The Consultant will contribute to the presentation of the results from the study at a National Consultative Meeting in the country within the framework of Equi-Health project.

   - The Consultant will consider the recommendations and conclusions from discussions at the NCC and reflect them in the final version of the national progress report.

Activity 6: Finalization of deliverables

1. The final output of the work will be the **report from a multi-stakeholder perspective on the implementation of the NRIS and other national commitments in respect to Roma Health** in [country], complemented by:

   - A power point presentation, and

   - A fact sheet document, in English and the country national language, summarizing the research findings and outlining recommendations for follow-up actions

   - Individual stories/ quotes/ perspectives (in the form of boxed stories, etc.) and photos (taken with all due acquiescing of involved persons) for further dissemination of project activities.

Structure and content of the progress report *sample*

The progress report will incorporate the results from the desk research, stakeholder interviews and the case study.

The progress report should be organized according to the following structure:

A. Executive Summary

B. Introduction

C. Background/ overview of the situation (method: desk research)

- **Number of Roma population** (official statistics & unofficial estimations of Roma national/ Roma migrants/ Roma third-country nationals)
- **Data/information from desk research** (literature, legal and policy review) on Roma population health status, health needs and barriers in access to basic, emergency and specialized health care services

D. Overview of policy developments at national level from a multi-stakeholder perspective (method key stakeholder interviews)

- NRIS:
  - overview of the process of development, main national stakeholders involved, process of decision of health priorities, development of action plan and linkages to other national programmes (health program, etc.), implementation and/or process of revision of strategy, funding mechanism, monitoring mechanisms, planned evaluations of the NRIS);
  - EC evaluation of the NRIS and country specific recommendations: main challenges identified in terms of health and respective MS actions;
- Other health programmes/ relevant national programmes in respect to Roma health (i.e. EC funded programmes in the field regional development, education, employment, etc.);
- EU context: it is also important to outline in the report how the national strategies (and actions) relate and contribute to the EC policies on health inequalities, with particular attention to the Europe 2020 Strategy for smart, sustainable and inclusive growth, COM(2009) Solidarity in Health: Reducing health inequalities in the EU, the EU cohesion policy and other EU strategic documents listed in Annex I.

Special focus need to be devoted to the following priorities, listed in the EC Communication "National Roma Integration Strategies: A first step in the implementation of the EU framework" (May 2012) as part of an integrated approach to healthcare:

- Extend health and **basic social security coverage** and services (also via addressing registration with local authorities);
- Improve the **access of Roma**, alongside other vulnerable groups, to **basic, emergency and specialized services**;
- Launch **awareness raising campaigns** on regular medical checks, pre- and postnatal care, family planning and immunization;
- Ensure that **preventive health measures** reach out to Roma, in particular **women and children**;
- Improve **living conditions** with focus on segregated settlements

E. Overview of policy developments at local/municipal level from a multi-stakeholder perspective (method key stakeholder interviews)

- Roma Integration strategy at local level (process of adoption, implementation and challenges as to NRIS, main actors involved, link to other local programmes/initiatives, funding)
- Other health programmes implemented on local/municipal level (i.e. EC funded programmes in the field regional development, education, employment, etc.);

F. Case study ***[country specific]***

- Results from the case study

Annex

A summary and key findings concerning all interviews, structured according to relevant categories that will have been emerged as the result of the qualitative research are expected to be annexed to the progress report, complemented by photographs (taken with appropriate approval is persons are recognisably shown).

Format

The progress report will comprise of desk research, field research and case study/ies, for a total of approximately 24,000 words (around 60 pages), excluding tables and annexes. **The final length of the report may change depending on the country context.**

The report should be prepared in English, at a proof-reading quality and submitted in MS Word, single spaced, Times New Roman, font size 12 format and sent by e-mail to ROBrusselsMHUnit@iom.int.

Any data used for graphs or tables should also be provided in Excel format for editing purposes. A bibliography with all the sources analysed – both in English and in the national language - should be inserted following the IOM style guide.

Application process

In order to be selected for a national Consultant, the applicant shall submit a proposal (up to 10 pages) and a CV, outlining relevant research experience in the field of migration and ethnic minorities' health to the Migration Health Division, RO Brussels. The proposal should provide a brief overview of the situation in country in respect to Roma health, methodology for research, suggested list of respondents for key stakeholder interviews and an initial proposal for a case study research.

Deliverables/Outputs

The work should begin immediately after the signature of the contract.

1. No later than two weeks after the signature of the contract, the national Consultant shall submit **the final list of potential stakeholders for key informant interviews from a multi-stakeholder perspective, methodology, draft questionnaire(s) as well as a detailed work plan** to the Migration Health Division, RO Brussels.
2. No later than one month after the signature of the contract, the Consultant should submit the **draft desk review, update as to the on-going interviewing process with key stakeholders and provide a proposal for case study.**

   IOM might suggest a few additional interviews with stakeholders based on the results from the desk research.
3. No later than 31 January 2014, the Consultant shall submit **a draft progress report including new and generated qualitative data**.
4. No later than 31 February 2014, the Consultant shall submit the **second draft of the progress report which should incorporate all the findings from the research (if not previously) from the case study /interviews**. The report shall be in English, in accordance with the provided guidelines, and include an overview on statistics, summary and key findings of interviews, and any report(s) on additional data/ material/ information/ documents.
5. No later than 20th March, the Consultant shall submit **the final progress report, a ppt presentation, a fact sheet presenting the research results and individual stories/quotes/photos for further dissemination of project activities**. Some final clarifications and revisions might be requested until the end of March when the progress report should be finalized.

Reporting:

The national Consultant will coordinate closely with MHD RO Brussels the preparation and conducting of the research, as well as the drafting of the final progress report.

The national Consultant will report to the Migration Health Division, RO Brussels and keep them apprised of any developments which could affect the implementation and timelines during the course of the study.

By the 10th day of each month for the duration of the contract the Consultant must submit a brief written progress report to the IOM Migration Health Project Officer based in Sofia, Bulgaria. These should respectively detail activities, undertaken in the above mentioned research project and time spent on these activities.

Timeline for the Consultancy: November 2013 – April 2014

Remuneration: Negotiable, subject to previous experience, skills

Required competencies of the lead researcher:

a) PhD or equivalent experience in the fields of social research, public health, migration and ethnic minorities' health or related fields;

b) Experience in conducting quantitative and qualitative social research;
c) Excellent English writing skills;
d) Excellent communication and negotiation skills;
e) Experience in liaising with governmental authorities, national/regional and international institutions, including research institutes and universities;
f) Ability to work harmoniously and effectively in a multinational, multidisciplinary team;
g) Previous research experience or work on Roma health would be a definite advantage.

The national Consultant should ideally be based in the country where the work is to be done.

Annex I: Sources of information

EU strategic documents

DG REGIONAL POLICY (http://ec.europa.eu/regional_policy/index_en.cfm) (with focus on EU Structural funds and Roma inclusion policy in EU MS incl. specific recommendations for MS with Roma population)

DG JUSTICE (**http://ec.europa.eu/justice/discrimination/roma/index_en.htm**)

DG EMPLOYMENT AND SOCIAL AFFAIRS
(http://ec.europa.eu/social/main.jsp?langId=en&catId=750)

http://ec.europa.eu/europe2020/making-it-happen/country-specific-recommendations/
(with focus on country specific recommendations in relation to social inclusion of Roma population)

Communication from the Commission Europe 2020 **A strategy for smart, sustainable and inclusive growth** (with focus on country specific recommendations in relation to inequalities in health and Roma)
(http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:2020:FIN:EN:PDF)

EU Communication "Solidarity in health: reducing health inequalities in the EU" (2009)

Council conclusions on the Inclusion of Roma and the Common Basic Principles on Roma inclusion (2009)

EC Communication on EU framework for National Roma integration strategies up to 2020 (2011)

Council conclusions on an EU framework for National Roma integration strategies up to 2020 (2011)

European Parliament Resolution on the EU strategy on Roma inclusion (2011)

EU Communication "The social and economic integration of the Roma in Europe" (2010)

EC Communication "National Roma Integration Strategies: A First Step in the Implementation of the EU Framework" (May 2012)

EC, Steps forward in implementing national Roma integration strategies (2013)

EC, Proposal for a Council recommendation on effective Roma integration measures in Member States (2013)

EP motion for a resolution on strengthening the fight against racism, xenophobia and hate crime (2013)

(http://www.europarl.europa.eu/sides/getDoc.do?type=MOTION&reference=B7-2013-0123&language=EN)

FRA The progress of Roma in 11 EU Member States, Survey results at a glance (2012)

Roma platform website
(http://ec.europa.eu/justice/discrimination/roma/roma-platform/index_en.htm)

CoE

Protecting the rights of Roma (2011)

Human rights of Roma and travelers in Europe (2012)

ROMED programme (I and II phases)

Romact programme

Good practices database (with special focus on health practices in the database)

IOs

Interagency Coordination Initiative *Scaling up action towards Millennium Development Goals (MDGs) 4 and 5 in the context of the Decade of Roma Inclusion and the National Strategies for Roma Integration*

UNDP Thematic reports: Roma Inclusion Papers series, counry reports, online database of the UNDP Regional Centre for Europe and the Community of Independent States;

Reports of CSOs

European Roma Policy Coalition, Analysis of the national Roma integration strategies / European Roma Policy Coalition, 2012

European Roma Information Office, The European Commission's main achievements in Roma inclusion/ 2012

EUroma (European Network on Social Inclusion and Roma under the Structural Funds) Facts by country

OSI

Roma Health Mediators Successes and Challenges (2011)

Beyond Rhetoric: Roma Integration Roadmap for 2020 Priorities for an EU Framework for National Roma Integration Strategies compiled by Bernard Rorke, International Research and Advocacy Director for the Open Society Roma Initiatives (2011)

Critical Review of EU Framework National Roma Integration Strategies (NRIS), Open Society Foundations Review of NRIS submitted by Bulgaria, the Czech Republic, Hungary, Romania and Slovakia (2012)

Decade of Roma inclusions (http://www.romadecade.org/)

- Decade Progress reports (2010, 2011, and 2012)
- Civil Society Monitoring reports (2012)
- Other relevant publication to HEALTH

DG SANCO funded projects

- Mighealthnet

http://mighealth.net/eu/index.php/Roma_%26_Traveller_communities

http://mighealth.net/eu/index.php/3._Projects_on_Roma_health

- Roma Health Project

Health and the Roma Community, Analysis of the Progress in Europe. Bulgaria, Czech Republic, Greece, Portugal, Romania, Slovakia, Spain (http://ec.europa.eu/justice/discrimination/files/roma_health_en.pdf)

Apéndice B

Escobar-Ballesta, M., Garcia-Ramirez, M., & De Freitas, C. (2018). Taking stock of Roma health policies in Spain: Lessons for health governance. *Health Policy, 122*, 444-451. doi:10.1016/j.healthpol.2018.02.009

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Taking stock of Roma health policies in Spain: Lessons for health governance

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ABSTRACT

Roma health inequities are a wicked problem. Despite concerted efforts to reduce them under the Decade of Roma Inclusion initiative, the health gap between Roma and non-Roma populations in Europe persists. To address this problem, the European Commission devised the National Roma Integration Strategies (NRIS). This paper provides a critical assessment of the implementation of the NRIS' health strand (NRIS-H) in Spain and proposes an evaluation tool to monitor Roma health policies – the Roma Health Integration Policy Index (RHIPEX). It also makes recommendations to promote Roma health governance. To achieve these goals, four community forums, 33 stakeholder interviews and a scoping review were conducted.

Results show that the NRIS-H implementation is hindered by lack of political commitment and poor resource allocation. This has a negative impact on Roma's entitlement to healthcare and on their participation in decision-making processes, jeopardising the elimination of the barriers that undermine their access to healthcare and potentially contributing to reproduce inequalities. These unintended effects point out the need to rethink Roma health governance by strengthening intersectional and intersectoral policies, enabling transformative Roma participation in policymaking and guaranteeing shared socio-political responsibility and accountability.

1. Introduction

The Roma have considerably poorer health outcomes when compared to non-Roma populations across Europe [1,2]. Studies point to a persistent health gap with Roma experiencing lower vaccination coverage, higher levels of communicable and non-communicable diseases, higher unmet health needs and higher infant mortality rates, while acknowledging definitional and methodological challenges that limit data comparibility and impact the depth of the evidence base [1,3–8]. In 2005, twelve European countries joined efforts to promote Roma health equity through the Decade of Roma Inclusion – a political commitment to tackle the root causes of poor Roma health by enabling the participation of Roma representatives in health governance [9]. However, with the end of the Decade in 2015, it is clear that the health gap between Roma and non-Roma has not been closed [9–11]. Moreover, the persistent, interdependent and dynamic nature of Roma health inequities makes it a wicked problem [12], i.e. a problem over which there is little agreement on its causes and the best way to address them and that defies the capacity of any one organisation to solve it [13]. It is urgent thus to elicit innovative strategies to ensure Roma health governance, i.e. to assess and overcome the asymmetries in the distribution of the economic, intellectual, normative and political resources that affect Roma's health [14].

Foreseeing this challenge, the European Commission devised an EU Framework for National Roma Integration Strategies (NRIS) in 2011 [15]. The NRIS commits EU member states to monitor, share and strengthen Roma approaches in European policies by a) reducing the gap between policy planning and implementation; b) fostering intersectoral work and stakeholder leadership; c) engaging the Roma in decision-making and implementation processes; and, d) establishing evaluation systems to ensure the accountability and sustainability of political efforts. This paper takes stock of the implementation of the NRIS' health strand (NRIS-H) in Spain using a tool specifically designed to enable stakeholder engagement in the evaluation process. In so doing, it allows drawing various lessons for Roma health governance.

In light of Spain's migratory context, a distinction is made between 'national Roma', i.e. Roma people born in Spain (Kale or

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gitanos), and 'foreign Roma', i.e. Roma immigrants in Spain who originate predominantly from Eastern European countries (e.g. Romania, Bulgaria). The term 'Roma' is used to refer to both groups [16].

1.1. Roma health in Spain

In Spain, the Decade's National Action Plan aimed to improve Roma's access to and use of healthcare services, ensure Roma's health monitoring and reduce Roma health inequalities [17]. However, two national surveys on the health of national Roma conducted at the beginning and at the end of the Decade revealed little progress [18,19]. Roma people surveyed in 2014 continue to report poorer self-perceived health, higher rates of non-communicable diseases (e.g. cholesterol, hypertension, obesity, diabetes), mental health problems (e.g. depression) and tobacco consumption, and less phisical activity when compared to non-Roma [19]. They also experience barriers in accessing services that are partially covered by the National Healthcare System (NHS) (e.g. oral care) [19]. Although the national surveys do not include foreign Roma, a study conducted in Catalunya shows that they also have a poor health status and appear to have even less access to healthcare than national Roma [20].

The challenges undermining the creation of a robust evidence base on Roma health in Spain (e.g. constraints to survey undertaking, definitional inconsistencies) extend to other European countries [5,6,8,9,21,23]. Nevertheless, international evidence generally points to Roma being subject to greater vulnerability for social exclusion, unemployment, poverty and a low educational level that continue to hinder their access to the social determinants of health [2,5,6,21] despite political commitment to address the problem. In its intersection with ethnicity, gender, age and migration status, limited access to the social determinants of health works to produce a gradient of vulnerability in which women, children and foreign Roma are at greater disadvantage [4,7,24,25].

The Decade's relative failure has led its signing members to agree on a new referent framework under the NRIS. In Spain, the NRIS-H and its Operational Plan adopted in 2014 [26,27] proposed a reorientation of healthcare services towards equity and cultural diversity, training of health professionals and community agents in cultural competence, and the establishment of mechanisms to promote intersectoral work and Roma participation. A key element of the NRIS-H is to ensure the monitoring of policies from a multiple stakeholder perspective by enabling all actors with a stake in Roma health to participate in policy assessment and reformulation on an equal footing.

1.2. Roma health inequities as a wicked problem

Traditional policy approaches have sought to address Roma health inequities with quick and linear fixes that go from problem to solution uncritically [13]. However, Roma health inequities have persisted, not just because of the social shortcomings that are prone to arise when seeking to solve problems of great complexity but also due to the lack of a robust evidence base on which to ground policy. Research on Roma health is scarce, fragmented and often small-scale [5,8,9,21]. This constraints a thorough assessment of the mechanisms underlying Roma health inequities and the set up of effective health monitoring systems, causing policy to be produced in a piecemeal manner and with disregard to the various gradations of exclusion that impact Roma health. Acting toward an equitable distribution of the social determinants of health among the Roma requires participatory governance for health, i.e. participation by all stakeholders in problem framing, priority setting and decision-making.

Roma health governance involves multiple stakeholders (e.g. Roma and non-Roma people, civil society organisations—CSO, health professionals, policymakers) with competing values and conflicting goals [12]. Moreover, both these stakeholders and evidence on Roma health inequities evolve at the same time that policymakers are trying to address the problem [12,15,28]. Having neither a definitive formulation nor a straightforward solution, Roma health inequities typically disallow for trial and error learning. As a result, 'every solution to [this] wicked problem is a one-shot operation' [12,p.163] that can lead to paradoxical and unforeseen consequences. The promotion of Roma participation in policy-making encouraged by the Decade and NRIS' frameworks is a case in point of these unintended effects. Roma health stakeholders are not on an equal standing, to the obvious disadvantage of Roma people. As a result, policy has been developed and assessed by stakeholders working from within or closer to decision-making bodies (e.g. policy-makers, managers). The exclusion of health professionals, CSO and Roma from policy-making has caused policies to become disconnected from Roma's needs and values and to fare poorly in terms of implementation [5,6,29]. Yet, where opportunities for Roma involvement in policy-making have arised they have been often coopted by actors who claim to represent Roma's interests but who are not acknowledged by Roma people as their legitimate representatives [9,23,30]. By failing to produce a response to Roma's needs, while allocating Roma health resources to attend to the needs of other interest groups, participatory exercises of this kind risk contributing to reproduce existing health inequities. Dealing with Roma health inequities from a wicked problem perspective thus demands a tailor-made approach to Roma health governance [12–14,28] that can foster transformative policy change [31].

Transformative policy change refers to changes in policy that resort to the best available evidence and incorporate all stakeholders' views and values into decision-making. Transformative Roma health policy should therefore aim to: a) promote the strengthening of the evidence base to enable the identification of the underlying causes of Roma health inequities; b) ensure Roma participation in policy formulation, implementation and assessment through inclusive and reliable participatory exercises; and c) enable the involvement of all stakeholders in devising solutions, allocating resources and implementing actions to address Roma health inequities. To achieve this, both an evidence-based and a discursive approach need to be used [31]. The former focuses on the use of scientific evidence, while the latter recognises the power of discourse in translating particular groups' values and perspectives into courses of action. This paper aims to assess the implementation of the NRIS-H in Spain using a transformative policy change framework [31] with the final purpose of promoting Roma health governance. To do so, it draws on an evaluation tool specifically designed to incorporate both scientific evidence and stakeholder input – the RHIPEX.

2. Methods

This study entailed a recursive and iterative process to monitor the implementation of the NRIS-H in Spain through the development of a tool to assess Roma health policies – the Roma Health Policy Integration Index (RHIPEX). In 2014, a partnership was established between two groups of stakeholders in the Spanish regions with the highest proportion of Roma people: a) researchers from the Centre of Community Research and Action at University of Seville (CESPYD) in Andalusia; and b) policymakers from the Public Health Agency of Catalonia (ASPCAT). This partnership developed the RHIPEX inspired by the Migrant Integration Policy Index [32], a tool that evaluates and compares governmental policies and actions

Table 1
Roma Health Integration Policy Index (RHIPEX): dimensions and indicators.

Dimensions	Indicators
Entitlement to healthcare	*Requirements for obtaining entitlement:* formal and informal requirements for national and foreign Roma's access to the national healthcare system (NHS). Includes aspects related to the Health Card application process and other requirements related to forms of identification, registration, etc. *Co-payments:* frequency of out-of-pocket payments for medical care made by the Roma and cases of exemption from payment (e.g. low income, chronic diseases). *Coverage*: list of services to which the Roma population has access. Distinguishes between healthcare coverage for national and foreign Roma.
Access to healthcare	*Accessibility barriers:* barriers that hinder national and foreign Roma's access to the NHS. These barriers may be related to Roma's culture, derive from the system and its providers, etc. *Policies and adaptation strategies to suppress accessibility barriers:* policies developed and implemented through local, regional or national plans intended to tackle accessibility barriers. Also entails specific actions developed by providers of healthcare centres or civil society organizations to eliminate these barriers.
Responsiveness of healthcare services	*Health inequalities identified in the NRIS*: includes inequities described in the Operational Plan 2014–2016 and their critical appraisal. *Policies to make healthcare services more responsive:* includes aspects related to the training in cultural competence of service providers. *Healthcare services and providers' adaptation strategies:* measures adopted by healthcare providers and some healthcare centres to adapt to the characteristics and needs of national and foreign Roma population.
Achieving and sustaining change	*The political and economic context of the NRIS:* healthcare system's capacity to achieve the objectives of the Operational Plan of the NRIS. The focus is placed on how these objectives are shaped by current restrictions imposed on the NHS. *Organizational movement, participation and collaboration of the Roma community*: relationships between national and foreign Roma, Roma organizational movement and participation, as well as collaborative relationships between different organisations and how they contribute to improving Roma health. *Collaborative work among multiple stakeholders*: synergies between different organisations and how they contribute to improving Roma health and wellbeing. These organisations include local, regional and national institutional bodies, healthcare and academic institutions, Roma associations, social organisations and NGOs.

aimed at promoting and improving the integration of migrant and ethnic minority populations across different policy sectors. RHIPEX also nourishes from the indicators proposed by the WHO's assessment recommendations for the NRIS-H [33] and the Decade's Roma Inclusion Index [10] and lays foundation on migrant health policy frameworks [34,35] and insights on how to improve Roma health policies' effectiveness [1]. As a result, RHIPEX consists of four dimensions: a) entitlement to healthcare, b) access to the healthcare system, c) responsiveness of healthcare services, and d) achieving and sustaining change. A set of indicators corresponds to each of these dimensions (see Table 1).

The NRIS-H's assessment involved a recursive data collection and analysis process between February and December 2014 from three sources: a scoping review of published documents, community forums and stakeholder interviews. The scoping review was used to identify evidence on Roma health and official perspectives about the NRIS-H implementation. The community forums and interviews were key in identifying evidence gaps, dissonances between official and stakeholders' perspectives of NRIS-H impact and strategies to overcome its fragilities.

The CESPYD-ASPCAT partnership created a stakeholder platform composed of 48 representatives from 25 institutions (e.g. Roma CSO, hospitals, primary healthcare centers, regional and local governments, universities) with relevant roles in the field of Roma health in Spain, including policymakers, managers, researchers, healthcare professionals, social workers, Roma representatives, mediators and technicians (see Appendix A). Two community forums involving members of the partnership and the stakeholder platform were held in Andalusia and Catalonia at the beginning of the study to invite stakeholders to participate in the assessment. Following an interview guide based on RHIPEX's indicators, interviews with 33 stakeholders were later conducted with stakeholders in Andalusia (n = 15) and Catalonia (n = 18) by two researchers. The forums and interviews were audio recorded with participants' informed consent and transcribed verbatim.

At the same time, a scoping review of scientific literature, policies and plans on Roma health in Spain published between 2005 and 2014 was conducted. Materials from the beginning of the Decade, three research papers and four legal documents prior to 2005 were also included given their relevance for the assessment. Electronic databases (MEDLINE, PubMed, PsycINFO, Google Scholar) and 25 websites of organizations (e.g. national and regional health departments, Roma and non-Roma CSO, international and European institutions) were searched using a combination of keywords following three topical areas: a) health policy (policy; strategy; plan); b) population (Roma; gypsy); and c) study setting (Spain; Andalusia; Catalonia). During the community forums and interviews; stakeholders suggested another 14 documents. From the 145 publications identified; 36 were included in the study following the WHO's analytic framework to review the NRIS-H [33] (see Appendix B).

Data collected through the interviews and the scoping review were coded and content analysed using the Atlas.ti 5.0 software. RHIPEX's indicators served as *a priori* code system, to which were added categories derived inductively from the data. The analysis was conducted independently by two researchers assisted by a third who exchanged and compared results to eliminate discrepancies. Data quality was further ensured through two community forums organized at the end of the study in Seville and Barcelona to share and discuss the findings with the CESPYD-ASPCAT partnership and the stakeholder platform.

3. Results

Results concerned with the NRIS-H implementation are presented following RHIPEX's structure: entitlement to healthcare, access to healthcare, responsiveness of healthcare services, and achieving and sustaining change. They are illustrated by direct quotes drawn from the interviews (Table 2) and supported by literature from the scoping review.

3.1. Entitlement to healthcare

The Spanish NRIS-H was designed at a time when the NHS provided universal coverage for both national and foreign Roma in the same grounds as for Spanish citizens [36]. In 2012, amidst the

Table 2
Stakeholders' perspectives on the NRIS-H implementation.

1	**Entitlement to healthcare**
1.1	'I can't prescribe them medicines because they are not in the system' (HP1)
1.2	'They have no documents at all (. . .) We have no information about their family structure' (PM1)
1.3	'The consulate charges them for the authentication of documents, a thing that shouldnít be doing' (PM3)
2	**Access to healthcare**
2.1	'In many centres they say "no" straightaway to the Roma (. . .) minors, pregnant women, emergencies' (SW2)
2.2	'NHS isn't ready professionally to deal with exclusion, manage diversity, work in conflict areas. . .' (HM1)
2.3	'They are all equal so we don't have to implement positive discrimination with the Roma' (M2)
2.4	'They lack of compliance with basic codes of conduct. (. . .) So conflicts arise but not related to assistance or equity' (M3)
2.5	'A patient may come here with a backache and painkillers are prescribed, but the fact this person sleeps on the floor goes unnoticed' (HM1)
2.6	'There is not a mediator in the centre to be a referent for Roma patients (. . .) It is not compulsory' (PM2)
2.7	'The sure thing we know about foreign Roma is that we know nothing' (PM1)
2.8	'They don't keep appointments, use emergency services a lot and do not continue treatments' (HM1)
2.9	'We run a community project to include families in the system (. . .) Mediators call me [and] I accompany [Roma users] to the reception desk, we do all the paperwork, I clarify things for them' (SW4).
2.10	'In the health mediation program we develop a census to visit settlements and locate excluded Roma' (HM3)
3	**Responsiveness of healthcare services**
3.1	'[NRIS-H's priorities] don't really fit our reality (. . .) a more global perspective is necessary to bring out the real needs of the Roma (. . .) It is extremely biomedical and it focuses on unrelated points' (M5)
3.2	'Regarding the integration of policies and allocation of resources (. . .) we miss the transversality of Roma within these' (M4)
3.3	'[NRIS is] a declaration of principles that would need to be implemented but remains up in the air' (M5)
3.4	'We are [changing] the way we work (. . .) we created a health committee and invited Roma women" (HM1)
3.5	'I have done some sort of visual collage (. . .) to smoothen the [communication] codes' (SW4)
3.6	'They don't really like doing things in groups (. . .) they are afraid or ashamed' (HP2)
3.7	'We proposed the mourning assistant since the Roma have specificities regarding death' (PM2)
3.8	'I've started to prescribe considering the price (. . .) They go to CSO Cáritas to get [the medicines]' (HP1)
3.9	'In the forty-day period after childbirth contraceptives are not generally prescribed. The Roma are [an exception because] some women get pregnant within one month of childbirth' (HP1)
3.10	'I call them if they miss an appointment and go to their places (. . .) so they have a proper follow-up' (HP3)
3.11	'The objectives set for doctors are linked to economic incentives and they aren't adapted (. . .) So if you refer patients four times and they miss the appointments, you're penalised' (HP1)
4	**Achieving and sustaining Roma health change**
4.1	'To implement [the NRIS-H] you have to provide a budget and see how it is articulated' (PM1)
4.2	'We see a lack of mobilization of the set of stakeholders responsible for [the NRIS] implementation' (M5)
4.3	'[The regional government] doesn't have orders from the State to make plans for the Roma (. . .) there is no obligation, neither administratively nor politically' (PM1)
4.4	'The Roma don't participate (. . .) Behind Roma CSO there are few Roma' (PM1)
4.5	'It has been easier to give them money than to empower them' (HM1)
4.6	'[The Roma organizational movement is not representative of] all the Roma but those who for one reason or another have been organized (. . .) its engagement within the community is quite limited' (M6).
4.7	'There are Roma who believe they are all equal (. . .) others feel more Spanish' (HM2)
4.8	'We can't give grants [to Spanish Roma CSO] if we want to help the foreign Roma [because] these are not going straight [to them]' (PM4)
4.9	'It's hard to find people working on Roma health, imagine finding somebody working for foreign Roma' (HM2)
4.10	'There is no positive discrimination [unless] programs applying for funding contemplate this' (PM1)
4.11	'In the most institutional and political dimensions problems arise and collaboration is scant' (HM2)
4.12	'The Roma shouldn't be called just to attend meetings (. . .) Non-Roma need to partially manage [fundings, but] if the Roma have organizations why shouldn't we be responsible of it?' (PM2)
4.13	'We [providers] know each other and have good relationships, we speak the same language' (HM2)
4.14	'We aren't well coordinated (. . .) All Roma CSO requires you to do something [very similar]" (HP1)

HP: healthcare professional; HM: health mediator; SW: social worker; PM: policymaker; M: manager.

financial crisis, a right-wing government enforced Royal-Decree 16/2012 [37] arguing for the urgent need to guarantee the NHS's sustainability. This measure resulted in the transformation of the NHS from a tax-based system into an insurance-based system that restricted entitlement to healthcare to those affiliated to or insured by the Social Security System—except for pregnant women, chidren under 18 and emergency situations. Entitlement is strictly regulated through the Health Card: those who are not in possession of one are deprived of specialised services and drugs prescriptions (1.1) [37]. Regions such as Andalusia and Catalonia developed policies to alleviate the negative impacts of the Royal-Decree among the foreign population which resulted in several inconsistencies and unresolved questions [38,39]. Thus, the shift in entitlement took a toll on the most vulnerable members of the Roma community, causing many of them—mainly those without jobs or working in the informal economy—to be directly expelled from the NHS [40]. Stakeholders agreed with the report of the national Roma CSO Fundación Secretariado Gitano [40] which denounced the bureaucratic hurdles faced by foreign Roma in applying for a Health Card (e.g. registration at City Hall, dealing with consulates) (1.2–1.3); the provision of care to foreign pregnant Roma women only when it was directly related to pregnancy and the restrictions imposed to children even if they are covered by the Royal-Decree.

Besides, budget cutbacks and transference of health competences between institutions have led several primary and secondary healthcare services to close, causing Roma patients to quit treatments due to lack of information about or inability to move to other services [40]. Staff shortages have also caused the elimination of primary and pediatric care afternoon shifts causing Roma children to miss classes and delaying vaccination schedules [40]. Also, co-payments for pharmaceuticals were imposed leaving many medicines out of coverage and patients in debt with the NHS have increased [40]. Roma's entitlement to care has thus been reduced both at the point of entry and in terms of the range of services available to them. The NRIS-H was not designed to anticipate and deal with these problems, nor was it revised in the meantime to overcome them.

3.2. Access to healthcare

According to stakeholders, Roma people are exposed to various barriers that undermine their access to care, even in situations of

emergency (2.1). Some stated that these accessibility barriers are linked to the NHS' lack of cultural competency (2.2), ethnocentrism (2.3) and outright stereotyping and discrimination (2.4) by some managers and professionals. Others noted that care provision tends to follow a biomedical model which disregards the social determinants that impact negatively on Roma's health (2.5). Other barriers pointed by interviewees include Roma's limited access to information due to the absence of health mediators that could facilitate their navigation of the NHS (2.6). Limited data on foreign Roma also makes it difficult to argue for policy aimed at adapting services to their needs (2.7). Stakeholders and the literature stated that the intersection of these barriers with cultural referentials, leads Roma to access the NHS through emergency services and to miss consultation appointments (2.8) [40–42].

Stakeholders explained that efforts to facilitate Roma's access to care are made on an *ad hoc* basis by some healthcare professionals and health mediators from CSO. These efforts include the use of informal census to locate potential users in settlements, navigation assistance and community health interventions (2.9–2.10). While this proves the potential of intersectoral collaboration and health mediation regarding access at local level, it also exposes NRIS-H limitations in eliminating accessibility barriers within the NHS.

3.3. Responsiveness of healthcare services

According to stakeholders, the NRIS-H prioritizes the effects (i.e. health problems) over the causes (i.e. social determinants) of Roma health inequities (3.1) and it should be updated toward the adoption of an holistic approach to Roma health. While our scoping review shows that regional and national plans intend to make the NHS more Roma-friendly through measures such as training professionals into cultural competence, publishing Roma health reports and guides, campaigning to adapt services to diversity and deploying mediators [17,43–46], stakeholders stated that most of these measures are neither transversal nor embedded within existing policies and find limited implementation on the ground (3.2–3.3).

For interviewees, where services have become sensitive to Roma needs that has been a direct result of local efforts. Health mediators from CSO have developed activities in healthcare centers such as trainings on Roma competence, translation services and workshops involving professionals and the Roma to increase mutual collaboration and understanding (3.4). In the absence of specific protocols for this population, some healthcare professionals working in areas with a high density of Roma service users have unofficially adapted their practice to Roma's needs. According to stakeholders, the strategies employed include using collages to facilitate communication (3.5), talking privately about sensitive matters (3.6) and taking religious and cultural beliefs into account (3.7). Taking notice of economic deprivation when prescribing drugs (3.8) and adapting reproductive healthcare protocols (3.9) are also important in protecting the most vulnerable Roma. All these adjustments require professionals to be highly proactive, watchful and coordinated in engaging users, particularly where follow-up care is concerned (3.10). Stakeholders stated that overexertions like these are not recognized by healthcare organizations, which may even penalize professionals for not achieving set performance goals that are incompatible with serving the Roma according to their contexts (3.11). The NRIS-H does not specify how to reconcile services' performance benchmarks with the additional demands associated with adapting care delivery to diverse populations.

3.4. Achieving and sustaining change

Interviewees asserted that the lack of a budget for the NRIS-H has hindered the allocation of resources to implement its set goals (4.1). In addition, literature shows that NHS cutbacks have weakened the impact of previous achievements in Roma health [40]. Moreover, limited commitment from those responsible for the NRIS-H, together with the decentralization of health governance into national, regional and local institutions, has made it unclear who should be held accountable for implementing and monitoring it (4.2–4.3).

The leading role of national Roma CSO has been a key asset in keeping up the NRIS-H agenda. However, stakeholders recognized some challenges that urge to be addressed. First, the involvement of Roma people in CSO is very low (4.4). Second, national Roma CSO are becoming increasingly bureaucratized and prioritizing a run for resources to secure the continuity of their programs. Third, CSO promote a subsidy-dependent culture among users rather than empowering and representing the Roma community as a whole (4.5–4.6). Finally, some national Roma CSO deliberately exclude foreign Roma from their programs, contributing to make this population one of the most underrepresented and invisible groups in Spain (4.7–4.9).

Although regional and national bodies have been established to promote dialogue and collaboration for Roma health (e.g. National Roma Council, Regional Ministries for Roma Population) [44], stakeholders stated that there are no measures to ensure Roma's participation in institutions (4.10) and reported difficulties in implementing intersectoral work at higher institutional levels (4.11). Some Roma representatives also argued for a more active role in policy formulation and implementation in decisions concerning their health (4.12). In contrast, intersectoral work at the community level (e.g. schools, primary healthcare centres, CSO) is flourishing (4.13): community roundtables, working groups and networks have been organised to promote Roma health locally. However, stakeholders feared that lack of coordination between independent programs with similar goals and catchment areas may lead to unnecessary wasting of meagre resources with potentially negative impacts for the sustainability of ongoing initiatives (4.14). Thus although NRIS-H offers an ideal framework to foster Roma participation and collaboration among stakeholders, it fails to ensure the resources and full-spectrum engagement necessary to achieve its goals.

4. Discussion

This paper provides a critical assessment of the NRIS-H implementation in Spain and proposes an evaluation tool to monitor Roma health policies – the RHIPEX, while arguing that Roma health inequities are a wicked problem. As this section unfolds, it also makes a set of recommendations to promote Roma health governance following a transformative policy change framework.

Results show that the NRIS-H provides a good referent to guide policy formulation at a national level. However, in the case of Spain, limited political commitment and insufficient resource allocation impede the full implementation of Roma health policy on the ground. This is evidenced by the limited investement made on building a robust evidence base on Roma health and the problems observed in guaranteeing Roma's representation in participatory policy-making, which resulted in the development of policies and services with low sensitivity to Roma's needs. NRIS-H poor enactment impends the enforcement of entitlement to healthcare among Roma' most vulnerable groups and defers the elimination of accessibility barriers within the NHS. Furthermore, it increases the burden endured by the professionals who act to overcome system inadequacies and reduces Roma's chances of representation in health decision-making processes. NRIS-H inadequate implementation appears thus to be paradoxically causing Roma health inequities in Spain to widen. These unintended effects point to the

shortcomings of off-the-shelf approaches to wicked problems [47] and sets forth the need to rethink Roma health governance. In what follows, proposals are made to set this exercise in motion.

Roma health governance calls for an intersectional approach to health. As our results show, Roma health inequities are associated not only with Roma's ethnic background but also with other social identities (e.g. age, gender, class, migration status) that combine to place some Roma groups in a position of even higher vulnerability (e.g. foreign Roma teenage mothers) [48]. Policies that focus on one of these social identities while neglecting the others risk perpetuating power asymmetries and reproducing inequities [49]. It is necessary thus to imbue Roma health policies with intersectionality to enable an equitable distribution of resources and actions, particularly among the Roma at the lower rungs of the vulnerability ladder [21].

Roma health governance calls for a health-in-all policies approach. Roma people experience lower educational levels, higher long-term unemployment, higher exposure to poor living conditions and higher rates of at-risk and absolute poverty and discrimination [5,10,50]. Successful public policies on education, sanitation, social services and discrimination are likely to have a positive impact on the social determinants of health with spillover effects to Roma health outcomes [1,44,51]. Roma health policies thus need to be developed from a systems-thinking perspective and foster multilevel partnerships between representatives of the various policy, professional and civil society sectors to jointly devise and implement intersectoral strategies to address Roma health inequities [52]. This requires building stakeholders' capacity to frame and communicate the problems at hand, procure resources and engage in participatory decision-making processes directed at improving Roma health [52,53].

Roma health governance calls for an advocacy approach. Policy making and implementation have traditionally been top-down processes led by decision-makers, where lay citizen participation is often used as a 'technology of legitimation' for *a priori* made decisions [54]. Conversely, Roma health governance advocates for transformative participation [55], i.e. for a process of engagement through which dominant discourses are challenged, and transformative change is produced, by enabling dialogic relationships that allow disempowered minorities such as the Roma to become involved in the decisions that affect their lives on a more equalitarian standing [56]. Enabling such a process in Spain will require local institutional stakeholders who are known to and respected by the Roma (e.g. academics, professionals) to work together with both national and foreign Roma communities to identify legitimate representatives, discuss their problems and establish priorities for action, and foster the skills necessary to advocate for their needs and influence decision-making (e.g. argumentation skills) [52,57]. Acting in this way, will require the creation of participatory mechanisms specifically designed to foster Roma participation in policy formulation, implementation and assessment, i.e. set up locally, resourced with translation services where needed, and mindful of cultural differences both within Roma groups and between Roma and the host society [58]. But above all, it will demand a redistribution of power among stakeholders and the incorporation of new roles: stakeholders who are not recognized as Roma legitimate representatives need to be replaced by advocates selected by Roma communities themselves. At the same time, institutional stakeholders will have to show openness to hearing Roma's concerns and to join them in advocating for responses to their needs (e.g. policy change, services reform, needs-based interventions). By embracing the role of Roma health advocates, institutional stakeholders will fare a better chance in building trust and support from Roma communities, acting as liaison between Roma and the NHS, and fostering change toward Roma participation equitable policy and service development. This, in turn, is likely to enhance Roma's access to the social determinants of health, increase their policy literacy and enable them to become more empowered advocates [14,59–61].

Roma health governance calls for a social accountability approach. The NRIS-H assessment highlights the need for strengthening the evidence-base on Roma health and promoting a systematic and equity-focused health impact assessment at local level [62]. For that to take place, the type of questions asked and the methods used to collect and analyse data need to be reconsidered [4,21,22,49]. Moreover, stakeholders need to be aware of the importance of monitoring, reporting and evaluating both capabilities and fragilities, and to embed that routine into their practices [63,64]. Simultaneously, public institutions and healthcare services need to promote leadership for assessment and to allocate resources to support these processes. These actions are crucial to guarantee shared socio-political responsibility, proactivity and accountability for Roma health governance among all stakeholders [14,62].

5. Conclusion

The WHO European policy framework for the twenty-first century [65] aims 'to significantly improve the health and well-being of populations, reduce health inequalities, strengthen public health, and ensure people-centered health systems that are universal, equitable, sustainable, and of high quality.' This is particularly challenging for voiceless ethnic minorities at high risk for vulnerability as are the Roma. This paper draws attention to the need for transformative Roma health policies based on a critical understanding that can challenge the unjust structures that act to maintain the *status quo* of this population [31]. Involving the Roma, and all the other stakeholders, in policy planning, implementation and assessment can help strengthen the evidence-base, infuse policy with people's values and enhance their sense of agency in promoting Roma health [22,59]. It may also foster Roma's empowerment [14,60,61]. In sum, Roma health governance requires a multilivel approach that acknowledges the importance of intersectionality, intersectoriality, advocacy, participation and social accountability in advancing a fair distribution of rights and opportunities through Roma communities.

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Conflict of interest

The authors state that they have no conflicts of interest.

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Appendix A. Supplementary data

Supplementary data associated with this article can be found, in the online version, at https://doi.org/10.1016/j.healthpol.2018.02.009.

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Apéndice C

Escobar-Ballesta, M., García-Ramírez, M., Albar, M. J., & Paloma, V. (en prensa). Salud Sexual y Reproductiva en Mujeres Gitanas: El Programa de Planificación Familiar del Polígono Sur. ***Gaceta Sanitaria.*** **doi:10.1016/j.gaceta.2017.12.006**

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Original

Salud sexual y reproductiva en mujeres gitanas: el programa de planificación familiar del Polígono Sur

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RESUMEN

Objetivo: Describir los desafíos, recursos y estrategias del equipo de planificación familiar del Centro de Salud Polígono Sur de Sevilla en su atención a mujeres gitanas.
Método: Estudio cualitativo descriptivo en el que se realizaron entrevistas en profundidad y grupos de discusión con todas las profesionales del programa, así como una revisión documental de este. La información fue analizada a partir del *Roma Health Integration Policy Index*, una herramienta que evalúa la titularidad, accesibilidad, sensibilidad y capacidad de cambio de los programas de salud para población gitana.
Resultados: Las profesionales encuentran numerosos desafíos para implementar el programa de planificación familiar con mujeres gitanas debido a las características de las usuarias, así como a la baja sensibilidad del programa hacia ellas. La ausencia de actuaciones específicas para mujeres gitanas dentro del programa de planificación familiar establecido por el distrito sanitario obliga a las profesionales a desarrollar adaptaciones y estrategias que aseguren servicios de salud sexual y reproductiva de calidad para sus usuarias.
Conclusión: Es necesario adaptar los programas de salud sexual y reproductiva dirigidos a mujeres gitanas a partir de: a) la detección, evaluación, sistematización y difusión de buenas prácticas; b) el desarrollo de actuaciones que contemplen las múltiples vulnerabilidades de esta población; c) el reconocimiento de profesionales que aboguen por la salud de estas mujeres dentro de sus organizaciones; y d) la promoción de la justicia reproductiva como fin último de estos programas.

Sexual and reproductive health in Roma women: the family planning programme of Polígono Sur in Seville (Spain)

Keywords:
Family planning
Sexual and reproductive health
Women
Ethnic groups
Professional practice

ABSTRACT

Objective: To describe the challenges, resources and strategies of the staff of the family planning programme of the Polígono Sur Healthcare Centre in Seville (Spain) in their care of Roma women.
Method: This is a descriptive study in which in-depth interviews and discussion groups were held with all programme professionals, including a documentary review of the programme. The information was analyzed based on the Roma Health Integration Policy Index, a tool that evaluates the entitlement, accessibility, sensitivity and capacity for change of health programmes for the Roma population.
Results: The professionals encountered multiple challenges to implement the family planning programme with Roma women due to the characteristics of the users and the low sensitivity of the programme towards them. The absence of specific actions for Roma women within the family planning programme, agreed to by the healthcare district, obliges professionals to develop adaptations and strategies to ensure quality sexual and reproductive health services for their users.
Conclusions: It is necessary to adapt sexual and reproductive health programmes targeted at Roma women by (a) detecting, evaluating, systematizing and disseminating good practices, (b) developing actions that address the multiple vulnerabilities of Roma women, (c) acknowledging professionals who advocate for the health of these women within their organizations, and (d) promoting reproductive justice as the goal of these programmes.

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Introducción

Los programas de planificación familiar en España no están siendo efectivos en la superación de las inequidades en salud sexual y reproductiva que sufren las mujeres gitanas. Estas mujeres tienen mayores tasas de embarazos no planificados, abortos e infecciones de transmisión sexual que el resto de la población[1–3]. Factores individuales, como el género, la edad y la pertenencia a un grupo étnico, en interacción con determinantes sociales tales como marcados roles de género, acceso limitado a información, condiciones de pobreza y segregación, condicionan su salud sexual y reproductiva y les impide disfrutar de las oportunidades que ofrece el sistema de salud[4–8]. En aparente paradoja, la Encuesta Nacional de Salud a Población Gitana de 2014 ha mostrado un aumento de las visitas ginecológicas respecto a la anterior de 2006[3]. Aunque estos datos hay que tomarlos con cautela debido a las limitaciones metodológicas que los autores señalan, algunos estudios muestran que las mujeres gitanas asimilan pautas estándar de planificación familiar tardíamente y con escaso impacto en su propia salud sexual y reproductiva[9]. De hecho, la evaluación de la Estrategia Nacional para la Inclusión de la Población Gitana (ENIPG)[10], realizada en 2014 por la Organización Internacional para las Migraciones (OIM), subraya que la limitada sensibilidad de los servicios de salud hace difícil que los avances en el acceso fructifiquen en la efectiva superación de estas inequidades (véase http://equi-health.eea.iom.int/images/NRIS_Spain_Final.pdf).

Esta misma evaluación ha constatado que algunos profesionales de centros de salud que atienden altos porcentajes de mujeres gitanas realizan adaptaciones no institucionalizadas para captarlas y adherirlas a sus programas de planificación familiar. Poner en valor y visibilizar estas prácticas es un paso previo para monitorizarlas, evaluar su impacto y extraer lecciones para su difusión en otros centro de salud. En el contexto de las iniciativas promovidas por la OIM para asegurar la implementación de la ENIPG en España, este artículo describe la experiencia del equipo de planificación familiar del Centro de Salud Polígono Sur de Sevilla en cuanto a los desafíos que afrontan, los recursos de que disponen y las estrategias que despliegan para atender a mujeres gitanas.

Método

Diseño de la investigación

Diseño descriptivo a partir de técnicas cualitativas, realizando tres entrevistas en profundidad, dos grupos de discusión y una revisión documental.

Ámbito de estudio

Desde 1989, el Centro de Salud Polígono Sur atiende a dos de los seis barrios que componen el distrito homónimo de Sevilla: Murillo y Martínez Montañés (conocido como «las tres mil viviendas»). En comparación con el resto de los barrios, estos son habitados por población gitana en más de un 80%, concentran mayores tasas de exclusión y marginalidad, tienen precarias condiciones de vida y disponen de escasos recursos sociosanitarios[11]. Este centro es uno de los de mayor movilidad profesional del distrito sanitario.

El Polígono Sur recoge en su Plan Integral[11] los únicos datos disponibles sobre la salud sexual y reproductiva de sus habitantes, que datan de 2006 y no son específicos para población gitana. Los embarazos adolescentes suponen el 17% del total, un 5% más que en el resto de la ciudad. El 35% de los embarazos son no planificados y el anticonceptivo más usado es el preservativo, aunque un tercio de los jóvenes no lo usa. La tasa de interrupciones voluntarias del embarazo (IVE) es del 6,6%, y de ellas el 12% se producen en adolescentes. El 80% de los casos son mujeres que ya son madres y el 25% ya se había practicado una IVE. En un 50% de los casos no habían utilizado anticonceptivos y el 64% no habían acudido a consultas ginecológicas.

Fuentes y técnicas de recogida de información

El trabajo de campo fue realizado por dos investigadoras y un investigador ajenos al centro de salud entre abril y junio de 2014. En primer lugar, se desarrollaron entrevistas en profundidad a la matrona, a una médica de familia y a una enfermera del programa de planificación familiar. El guion incluía preguntas abiertas semiestructuradas orientadas a explorar la experiencia de las profesionales en cuanto a desafíos, recursos y estrategias en su atención a las mujeres gitanas (tabla 1). En estas entrevistas se identificaron los materiales disponibles por el equipo del programa con el fin de realizar una revisión de ellos. Posteriormente, para ajustarnos a la disponibilidad de tiempo del equipo y alcanzar la saturación de la información, se organizaron dos grupos de discusión de una hora de duración cada uno con todas las profesionales del programa: una matrona, dos médicas de familia, dos enfermeras y dos auxiliares de enfermería; todas ellas mujeres con una experiencia en el centro de salud de entre 2 y 22 años (tabla 2). Los grupos de discusión permitieron profundizar las preguntas planteadas en las entrevistas, explorar otras cuestiones surgidas durante estas (relacionadas con el inicio del programa y la motivación del equipo) e incorporar la perspectiva del resto de profesionales (tabla 1). Los grupos de discusión y las entrevistas fueron grabadas y transcritas *verbatim* para su análisis.

Análisis de la información

La revisión documental del programa tenía por objetivo identificar los recursos materiales de que las profesionales disponían

Tabla 1
Guiones de las entrevistas en profundidad y grupos de discusión

Preguntas entrevista en profundidad
- ¿Cuáles son las principales dificultades que tienes para implementar el programa con mujeres gitanas?
- ¿Con qué recursos cuentas para favorecer el éxito del programa? ¿Son suficientes?
- ¿Has puesto en marcha otras estrategias o adaptaciones para asegurar que el programa sea sensible a las características y las necesidades de las mujeres gitanas?

Preguntas grupo discusión
- ¿Cuándo, cómo y por qué surge el programa de planificación familiar?
- ¿Cuáles son las principales dificultades que tenéis para implementar el programa con mujeres gitanas?
- ¿Con qué recursos contáis para favorecer el éxito del programa? ¿Son suficientes?
- ¿Habéis puesto en marcha otras estrategias o adaptaciones para asegurar que el programa sea sensible a las características y necesidades de las mujeres gitanas?
- ¿Creéis que el programa tiene éxito? ¿Por qué?
- ¿Qué os motiva para trabajar en un entorno de adversidad?

Tabla 2
Perfiles de las profesionales del programa de planificación familiar del Centro de Salud Polígono Sur

Profesión	Sexo	Tiempo en el centro de salud
Auxiliar de enfermería	Mujer	Más de 20 años
Auxiliar de enfermería	Mujer	12 años
Enfermera	Mujer	3 años
Enfermera	Mujer	5 años y medio
Matrona	Mujer	5 años
Médica de familia	Mujer	2 años y medio
Médica de familia	Mujer	10 años

para su implementación. Esta revisión se realizó mediante un análisis de contenido siguiendo el *Roma Health Integration Policy Index* (RHIPEX)[12] desarrollado por la OIM para evaluar la titularidad, accesibilidad, sensibilidad y capacidad de cambio de los programas de salud para población gitana. La información obtenida en las entrevistas y en los grupos de discusión se analizó con un sistema de categorías preestablecido que combinaba el objetivo del estudio y las dimensiones del RHIPEX. Todos los análisis fueron realizados independientemente por dos investigadoras utilizando la herramienta Atlas.ti 5, y con el apoyo de un tercer investigador para asegurar la fiabilidad entre jueces. Las notas de observación recogidas por el equipo de investigación durante las visitas al centro de salud complementaron la información obtenida.

Una vez redactados, los resultados se devolvieron en dos sesiones. La primera sesión fue organizada con el equipo del programa de planificación familiar del Centro de Salud Polígono Sur; la segunda, con la Mesa de Salud Comunitaria del distrito, formada por diversos agentes (profesores, gestores de servicios públicos, planificadores de políticas, etc.), entre los que se encontraba el director del centro de salud. Las personas participantes reflejaron la validez y la fidelidad de los resultados de acuerdo con sus experiencias, y señalaron la necesidad de diseminar y protocolizar las actuaciones en salud sexual y reproductiva con las mujeres gitanas.

Aspectos éticos

Se obtuvo el consentimiento informado de todas las profesionales para grabar los grupos de discusión y las entrevistas, asegurando el anonimato y el uso de la información exclusivamente para fines de investigación.

Resultados

Los resultados se presentan en función del objetivo del estudio (identificar desafíos, recursos y estrategias de las profesionales en su atención a las mujeres gitanas) y de las dimensiones del RHIPEX (titularidad, accesibilidad, sensibilidad y capacidad de cambio del programa).

El equipo de planificación familiar identifica como desafío la falta generalizada de documentación entre las mujeres gitanas (p. ej., DNI, certificado de nacimiento), lo cual, aunque no impide la atención, dificulta el acceso al historial, la prescripción de tratamientos o la derivación a especialistas (tabla 3, 3.1-2). El equipo también subraya la importancia de disponer de información sanitaria sobre población gitana, así como un sistema para evaluar el impacto del programa en mujeres gitanas más allá de sus propias percepciones (3.3). Según la opinión de las profesionales entrevistadas, otro importante desafío es que las mujeres gitanas no valoran los beneficios de involucrarse en el programa de planificación familiar porque: a) carecen de recursos y motivación para planificar cualquier ámbito de sus vidas a medio y largo plazo (3.4-5); b) algunas pautas del programa chocan con tradiciones y creencias arraigadas (3.6-8); c) sus parejas rechazan colaborar y respetar las prescripciones (3.9); y d) la adherencia de esta población a cualquier tratamiento médico que no suponga efectos inmediatos y visibles es baja (3.10). Igualmente, las condiciones de exclusión y marginalidad en las que viven suponen barreras para acceder y participar regularmente en el programa (3.11-12). Todo esto acaba afectando al funcionamiento del programa; por ejemplo, existe un gran incumplimiento de citas previas y al mismo tiempo muchas usuarias esperan ser atendidas de manera inmediata (3.13).

Tabla 3
Perspectiva de las profesionales del programa de planificación familiar sobre los desafíos y las barreras en su atención a las usuarias gitanas

Ref.	Desafíos de las profesionales
3.1	«Las principales barreras, administrativas (. . .) Tengo embarazadas de 14 años que no tienen DNI. Una ha llegado al caso de no constar en ninguna parte, no tiene siquiera certificado de nacimiento.» (MT-E)
3.2	«Ni puedes prescribir fármacos ni puedes hacer un montón de cosas. El que aparezca el nombre de una manera provisional [en el sistema] no te da una serie de derechos.» (MF1-E)
3.3	«No tenemos un registro de intervenciones específicas con población gitana. Son sobre todo percepciones que una tiene. Después los resultados serán los que sean, que muchas veces no se conocen.» (EN2-GD)
3.4	«No tienen una cultura de planificación ni para su alimentación (. . .) El concepto de prevención es muy difícil de transmitir. [Tienen] el concepto de la inmediatez para todo, para su vida cotidiana. . .» (AE2-E)
3.5	«Es una población que no tiene regularidad en la asistencia a un programa que realmente es de prevención, con lo cual ellas eso no lo ven como algo imprescindible.» (EN1-GD)
3.6	«En niñas de 14-15 es muy difícil prevenir [embarazos]. Después ya cuando tienen una edad es más fácil, pero el primero es muy difícil de evitar (. . .) Alguna se salva, pero para ellas es fundamental casarse, tener hijos y cuanto más pronto mejor, incluso te hacen consulta de fertilidad con 17 años.» (MF2-GD)
3.7	«Tengo dificultad [para trabajar con mujeres gitanas] porque tienen miedo, vergüenza... No sé en qué piensan ellas. Sus cosas son suyas y no les gusta compartirlas.» (MT-E)
3.8	«[Los implantes] son buenos y muchas lo aceptan, pero otras no, porque como no producen regla en la mayoría de los casos pues hay una cuestión cultural que no quieren quedarse sin regla.» (MF2-GD)
3.9	«Los hombres gitanos son muy difíciles, no participan en nada, muchas mujeres incluso vienen aquí a ponerse los métodos a escondidas de sus parejas.» (MF2-GD)
3.10	«Entonces los tratamientos o las enfermedades también es la inmediatez. . . Tiene que ser una medicación que notes el efecto, si no (. . .) es muy difícil transmitir [su] necesidad.» (MF1-E)
3.11	«Le das una cita para dentro de mes y medio a alguien que no tiene reloj, que no tiene agenda y que no tiene calendario, y dentro de mes y medio están en el mercadillo de Aracena o en Pamplona.» (MF1-E)
3.12	«Nuestro centro es característico [porque] las usuarias que han ido normalizando sus vidas saltan a vivir a otro sitio. Entonces llega una persona con una familia desestructurada y vuelves a empezar.» (AE1-GD)
3.13	«Hoy hemos tenido planificación, de las diez que había citado (. . .) han venido cuatro y dos que no tenían nada que ver con la cita.» (AE2-GD)
3.14	«Los médicos que estamos aquí tenemos un menor número de tarjetas sanitarias (. . .) Lo que pasa que aquí el único sitio que hay para ir al médico es este. Y vienen para todo. Además, aunque tenemos menos tarjetas, la población ambulante es muy grande y eso también distorsiona [el] cupo de enfermos.» (MF1-E)
3.15	«Y si le añadimos la presión, la poca adaptación del sistema cuando los objetivos van unidos a incentivos económicos, por ejemplo, menor prescripción de antibióticos (. . .) tenemos que estar prescribiendo amoxicilina porque ellos no tienen posibilidad de ir a los dentistas o no tienen una higiene dental adecuada. Tenemos una prescripción de antibióticos grandísima, de poco coste, pero casi continuo. Y claro, esto es para todos los centros de salud y para nosotros también.» (MF1-E)
3.16	«Empleas mucho tiempo, mucha energía en explicarles todas las cosas, en que tú veas que han comprendido, pero las vemos a la semana y no han comprendido nada.» (AE1-GD)
3.17	«Esto lleva mucho desgaste personal, tienes que tener una atención extraordinaria en las personas que tienes delante y tener un compromiso de servicio sanitario (. . .) Más allá del espectáculo de las Tres Mil Viviendas (. . .) hay unos problemas que no tengo ni idea de cómo resolver. Yo, como profesional sanitario, me siento desbordada (. . .) porque el servicio no lo siento nada adaptado a la demanda.» (MF1-E)

AE: auxiliar de enfermería; E: entrevista; EN: enfermera; GD: grupo de discusión; MF: médica de familia; MT: matrona.

Tabla 4
Roma Health Integration Policy Index: Guía de Actuación en el Programa de Planificación Familiar en el Distrito Sanitario de Atención Primaria de Sevilla

Dimensiones e indicadores RHIPEX		Guía de Actuación en el Programa de Planificación Familiar
Titularidad al programa	Titularidad de la población gitana	Cualquier usuario del Sistema Andaluz de Salud que acuda al servicio de planificación familiar del Distrito Sanitario Sevilla
Accesibilidad del programa	Utilización del programa por parte de la población gitana	No hay datos
	Mecanismos para identificar barreras de accesibilidad de la población gitana	No
Sensibilidad del programa	Correspondencia con la Estrategia Nacional para la Inclusión de la Población Gitana	Prioridades: tasa elevada de embarazos a edades tempranas y ausencia de revisiones ginecológicas
	Estrategias para mejorar la sensibilidad hacia la población gitana	No
	Políticas y estrategias destinadas a la formación o la adaptación de profesionales a la población gitana	No
Capacidad para conseguir y mantener cambios	Participación de la población gitana en el diseño y la implementación del recurso	No
	Colaboración intersectorial entre los agentes implicados	Sí, especialmente en actividades de promoción de la salud sexual y reproductiva en jóvenes *(Hora Joven)*. Actuaciones intersectoriales con educación y servicios sociales
	Mecanismos de ajuste y mejora	Protocolo de seguimiento del programa

Además, las profesionales afirman sentirse poco respaldadas por su institución. En este sentido, aunque el Centro de Salud Polígono Sur tiene una ratio de usuarios por profesional menor que otros centros debido a la mayor carga de trabajo asociada a los contextos de vulnerabilidad, esta ratio ignora la alta movilidad de la población (3.14). El sistema también ignora la necesidad de adaptar los objetivos de desempeño profesional a las características de las usuarias, llegando incluso a penalizar a algunas profesionales por su incumplimiento (3.15). Finalmente, el equipo reconoce que trabajar en planificación familiar con mujeres gitanas es una tarea ardua y lenta, y que conlleva un gran desgaste personal y profesional (3.16-17).

El principal recurso de que dispone el equipo del Centro de Salud Polígono Sur para implementar el programa es la Guía de Actuación en el Programa de Planificación Familiar en el Distrito Sanitario de Atención Primaria de Sevilla[13] (tabla 4). Elaborada en 2007, esta guía provee a las profesionales de información y herramientas para la atención integral de las usuarias respecto a anticonceptivos, infecciones de transmisión sexual, promoción de salud sexual y reproductiva en jóvenes, IVE, y derivaciones y registro en el sistema. Aunque la guía contempla una comisión encargada de mejorar el programa en función de las evidencias científicas y las carencias detectadas por las profesionales, no se ha realizado ninguna actualización que incorpore las recomendaciones de la ENIPG[10]. Así, la guía establece el derecho de todas las mujeres a usar y acceder al programa —sea por captación por parte de los médicos de familia o a demanda—, pero no hace mención específica a las mujeres gitanas. Tampoco contempla mecanismos para detectar y eliminar barreras de acceso, ni para adaptar sus prácticas y protocolos a esta población. No obstante, la guía incluye las prioridades en salud sexual y reproductiva recogidas en la ENIPG[10] (p. ej., prevención de embarazos en las adolescentes, incremento de las visitas ginecológicas). Las profesionales cuentan con otros recursos para apoyar la implementación del programa (p. ej., formularios, folletos, protocolos, guías, leyes, informes), organizados en tres ejes específicos (implantes subcutáneos, planificación familiar, salud sexual y reproductiva), que han sido elaborados por diversos organismos (Consejería de Salud de la Junta de Andalucía, Escuela Andaluza de Salud Pública, Distrito Sanitario de Atención Primaria de Sevilla, Organización Mundial de la Salud) (tabla 5). Al igual que la guía, estos recursos no cuentan con adaptaciones específicas para las mujeres gitanas.

La carencia de adaptaciones ha llevado al equipo a desarrollar estrategias informales no institucionalizadas. Para aumentar el acceso y la adherencia al programa, las profesionales realizan captaciones oportunistas de las mujeres gitanas en momentos clave (salas de espera, pediatría, pruebas de embarazo) (tabla 6, 6.1). También atienden a las usuarias sin cita previa en el momento de la captación (6.2), ajustan protocolos de revisiones o prescripciones de anticonceptivos (6.3-4), y consideran la situación económica de las usuarias para recetarles medicamentos baratos (6.5). Además, realizan un seguimiento activo y personalizado de las mujeres gitanas (llamadas telefónicas, visitas domiciliarias) (6.6) y desarrollan talleres en el centro de salud y en los centros educativos (6.7). Las profesionales reconocen poder manejar el contexto de exclusión y precariedad en el que trabajan gracias a los cursos de sensibilización facilitados por la Asociación FAKALI de la Red Equi-Sastipen-Roma del Ministerio de Sanidad, Servicios Sociales e Igualdad. Estos cursos de formación continuada permiten a las profesionales tomar conciencia de la historia de discriminación y de las tradiciones de la población gitana, de su salud y su relación con el sistema sanitario, así como sobre estrategias de intervención y promoción de la salud con dicha población (6.8).

El trabajo colaborativo dentro del grupo es considerado un activo muy valioso. Aunque cada una tiene su rol, todas están implicadas en las diferentes tareas del programa, especialmente en las captaciones y las derivaciones (6.9). Además, el trabajador social y la enfermera de enlace del centro de salud colaboran desarrollando actuaciones intersectoriales con otros agentes comunitarios. Las profesionales aseguran que su trabajo requiere una actitud abierta hacia la diversidad, empatía hacia circunstancias de vulnerabilidad y habilidad para gestionar conflictos y resolver problemas imprevistos (6.10-12). Esto les permite movilizarse para ofrecer una atención personalizada (6.13-15) que favorece entre sus usuarias una mayor adherencia al programa, un menor número de embarazos (6.16) y una mayor sensibilidad hacia la planificación familiar (6.17). Las profesionales sienten una alta motivación con el programa, con sus roles en él y con la respuesta de las mujeres gitanas (6.18), lo que favorece su sostenibilidad.

Discusión

Este estudio pone en valor la experiencia del equipo de planificación familiar del Centro de Salud Polígono Sur de Sevilla con mujeres gitanas. Los resultados muestran que las profesionales han logrado involucrar y mantener un número creciente de usuarias gracias a su compromiso y sobreesfuerzo en la captación oportunista y el seguimiento activo personalizado, en la gestión de la adversidad social en la que realizan su trabajo, así como en el desarrollo de sus competencias y las adaptaciones del programa a las mujeres gitanas. Entre estas, las profesionales recomiendan la recogida de datos sobre acceso y uso, la difusión del programa a las mujeres gitanas y sus parejas, el apoyo y el reconocimiento institucional de las profesionales, y el ajuste del programa y sus recursos a las recomendaciones de la ENIPG.

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Tabla 5
Documentos de apoyo del programa de planificación familiar del Centro de Salud Polígono Sur

Temas	Documentos	Referencias en línea disponibles
Implantes subcutáneos	Formulario de información y consentimiento informado escrito para implante anticonceptivo subcutáneo (Servicio Andaluz de Salud)	http://www.juntadeandalucia.es/servicioandaluzdesalud/hinmaculada/intranet/consentimientos/documentos/ap/IMPLANTE_ANTICONCEPTIVO.pdf
	Folleto informativo sobre implantes anticonceptivos subcutáneos para usuarias (Servicio Andaluz de Salud)	
	Protocolo de implantes hormonales subdérmicos (Servicio Andaluz de Salud)	http://studylib.es/doc/5987990/protocolo-implantes-hormonales-subd%C3%A9rmicos-abr-2013
Planificación familiar	Protocolo de anticoncepción de emergencia y test de gestación (Servicio Andaluz de Salud)	
	Guía *Forma Joven:* Una estrategia de salud para adolescentes y jóvenes de Andalucía (Escuela Andaluza de Salud Pública)	http://www.juntadeandalucia.es/salud/export/sites/csalud/galerias/documentos/c_3_c_1_vida_sana/adolescencia/guia_forma_joven2009.pdf
	Criterios para la indicación de implantes hormonales subcutáneos en el Distrito de Atención Primaria de Sevilla (Servicio Andaluz de Salud)	
	Protocolo y legislación de interrupción voluntaria del embarazo (IVE) en el Distrito Sanitario A.P. Sevilla (Servicio Andaluz de Salud)	
Salud sexual y reproductiva	Protocolo sobre relaciones interpersonales y sexualidad en personas con discapacidad física usuarias de centros residenciales (Consejería de Salud, Junta de Andalucía)	http://www.juntadeandalucia.es/export/drupaljda/Personas_Discapacidad_Protocolo_sobre_relaciones_interpersonales_y_sexualidad_pdint.pdf
	Actividades de promoción de la salud y consejos preventivos	
	Sexualidad: salud afectivo-sexual y reproductiva en la adolescencia (Escuela Andaluza de Salud Pública)	http://si.easp.es/psiaa/wp-content/uploads/2014/07/sexualidad_salud_afectivo_sexual_adolescencia.pdf
	Promoting sexual and reproductive health for persons with disabilities (World Health Organization)	http://apps.who.int/iris/bitstream/handle/10665/44207/9789241598682_eng.pdf;jsessionid=4B565CABC234B1CD4E24EC135F0A3DD0?sequence=1
	Sexual and reproductive health: a matter of life and death (World Health Organization)	http://www.who.int/reproductivehealth/publications/general/lancet_1.pdf

Tabla 6
Perspectivas de las profesionales del programa de planificación familiar sobre las estrategias empleadas con usuarias gitanas

Ref.	Estrategias desarrolladas por las profesionales
6.1	«Es captación proactiva, no solo desde la consulta de planificación, sino cuando estoy en otra consulta o en urgencias (. . .) La captación oportunista es imprescindible.» (EN1-E)
6.2	«Si [la matrona] desde su consulta, en una visita puerperal, detecta que han empezado las relaciones con penetración y hay riesgo para un futuro embarazo, aunque haga 20 días del parto, nos llama (. . .) y directamente le hacemos una prescripción (. . .) no tiene que coger cita.» (AE1-GD)
6.3	«No respetamos la planificación, no respetamos el tiempo por aquello de los riesgos... Más que no respetamos, adaptamos los protocolos a unas situaciones de alto riesgo. (. . .) En la cuarentena no se suelen prescribir anticonceptivos, pero en la población gitana es de las pocas poblaciones que sí los prescribimos (. . .) se quedan embarazadas en el primer mes después del parto.» (MF1-E)
6.4	«Muchas veces dejan de venir porque piensan que para una pastilla o ponerse otra cosa hay que hacerse una citología, hay que explorarlas, y eso a ellas [no les gusta]. Entonces, de primeras, no les hacemos ninguna exploración.» (MF2-GD)
6.5	«[Los bancos de fármacos] funcionan muchísimo, no solo para los que no tienen papeles, que no son tantos como los que no tienen dinero. (. . .) estoy prescribiendo sabiendo algunos precios porque me preguntan: ¿pero eso cuánto vale? (. . .) Salen de aquí y se van a Cáritas a por ellas.» (MF1-E)
6.6	«Sabemos que no es cuestión de dar una cita y ya relajarte y quedarte a la espera [. . .] Estamos siempre muy pendientes [. . .] y de llamar y de preguntar por sus actividades.» (MF1-E)
6.7	«Yo tengo mis talleres de educación maternal, de posparto, donde también las capto. Va funcionando porque intento no perderlas, las voy citando, nos vamos viendo y las voy educando.» (MT-E)
6.8	«Aquí han venido miembros de Fakali a dar charlas [. . .] sobre su vida, su estar o su sentimiento, de la historia del pueblo romaní...» (MT-E)
6.9	«Eso no lo tenemos escrito, eso lo tenemos hablado, hemos hecho formación conjunta, hemos visto la necesidad de coordinarnos más allá de lo que nos pide el programa de planificación, que es igual para todos los centros (. . .) Y luego tenemos una serie de acuerdos entre las personas que trabajamos en el programa (. . .) Todo el personal se implica en todo.» (MT-E)
6.10	«Somos personas cercanas. . . Aquí se valora mucho si tú conoces a la familia (. . .) y muchas veces a través de la familia atraes a la persona.» (EN2-GD)
6.11	«Empatía también, ponerte en el lugar de ellos, de lo que les ha tocado vivir, no lo han elegido y bueno, a veces te desespera, pero es lo que hace que te pongas en situación (. . .) Cuando ellos ven que tú te das a ellos, responden.» (AE2-GD)
6.12	«La comunidad gitana para mí son diferentes (...) me asombran constructivamente, me gusta ver esas diferencias, [. . .] para mí es satisfactorio. Si tú tienes esa curiosidad, pues se hace más razonable o más interesante tu trabajo, que muchas veces es muy petardo porque tiene muchos fracasillos.» (AE2-GD)
6.13	«Normalmente, o hay un programa de planificación con un solo profesional o han quitado el programa y cada médico se hace cargo de su población. . . Aquí el programa tiene que estar muy reforzado y lo cuidamos especialmente.» (MF1-GD)
6.14	«Cuando nos han dicho de quitar horas de programa nos ponemos: "pero bueno, ¿pero no veis lo necesario que es?" o [decimos] por qué pensamos que no se puede hacer como en otros centros, que realmente lo único que tienen es para una prescripción de anticonceptivos orales.» (AE1-GD)
6.15	«Yo voy a dar una asistencia sanitaria a una población con unas características. El dispositivo asistencial debería adaptarse a lo que tiene delante. Entonces, si esta población es demandante de inmediato, ¿tú qué haces poniendo una cita previa para un mes y no sé cuánto? Adapta el servicio para dar respuesta a esta característica poblacional.» (MF1-E)
6.16	«Yo lo estoy viendo [el éxito del programa] porque tengo menos embarazos (. . .) Y yo como les hago un seguimiento, porque vienen a verme como matrona, entonces pues veo que está funcionando.» (MT-E)
6.17	«Algunas madres gitanas han cambiado de mentalidad y ellas mismas te traen [a sus hijas, nueras] y te dicen "que se va a casar" para que les pongas pastillas, para que le pongas método.» (MF2-GD)
6.18	«Soy un punto de apoyo para la planificación de ellas (. . .) Tengo el respeto de mis usuarias, estoy consiguiendo que hagan un buen seguimiento (. . .) Estoy muy satisfecha porque vienen buscando a la matrona todo el tiempo. Siento que me necesitan y que soy útil para ellas.» (MT-E)

AE: auxiliar de enfermería; E: entrevista; EN: enfermera; GD: grupo de discusión; MF: médica de familia; MT: matrona.

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Aunque el trabajo no incorpora la perspectiva de las usuarias sobre el programa, futuros estudios deberían incluir su participación, así como profundizar en otros aspectos de su salud sexual y reproductiva (p. ej., casos de éxito y fracaso, papel de los hombres, maternidad temprana, identidad de género). No obstante, la fortaleza de este estudio radica en hacer evidente la necesidad de ajustar los programas de salud sexual y reproductiva para mujeres gitanas, y en esta dirección se proponen algunas lecciones.

La ausencia de datos y de adaptaciones dentro del sistema sanitario refleja su débil compromiso con la ENIPG[10], que convierte la salud sexual y reproductiva de las mujeres gitanas en un área libre de evidencias que las invisibiliza[14–16]. El escaso reconocimiento de las experiencias locales de éxito, como la que se presenta en este estudio, las convierten en casos aislados dependientes del voluntarismo de sus profesionales. Esto supone una falsa protección porque acostumbra a las mujeres gitanas a pautas eficaces no institucionalizadas. La Estrategia Nacional de Salud Sexual y Reproductiva[17], la Comisión Europea[18] y la OIM[12] promueven detectar, sistematizar y difundir estas buenas prácticas para prevenir la discriminación institucional, asegurar la visibilidad de las mujeres gitanas y rendir cuentas de las acciones implementadas[19–21].

Las actuaciones de las profesionales del Centro de Salud del Polígono Sur reflejan una aproximación intersectorial de la salud sexual y reproductiva basada en las características personales y en los determinantes sociales que confieren a las mujeres gitanas una mayor vulnerabilidad[4,6,22]. Foldes y Covaci[23] alertan sobre la inefectividad de esforzarse por conseguir que la población gitana que vive en contextos de exclusión acceda al sistema si los programas no son convenientemente adaptados. El desarrollo y la implementación de los programas de salud sexual y reproductiva dirigidos a mujeres gitanas deben reconocer sus diferencias y necesidades dentro de unos contextos sociales y políticos determinados[4,5,24,25]. Esta aproximación permitirá acceder a los colectivos más invisibles de la comunidad y superar orientaciones que culpabilizan a las víctimas y cuestionan su capacidad para gestionar su propia salud[26]. Bajo esta perspectiva, el sistema y sus profesionales ponen sus programas de salud sexual y reproductiva al servicio de sus usuarias, y no las usuarias al servicio de los programas, asumiendo una mayor responsabilidad en la provisión de cuidados sensibles y equitativos[20,27].

La efectividad de los programas de salud sexual y reproductiva con mujeres gitanas también depende de profesionales sensibles que, ante una realidad compleja, adquieren conocimientos, actitudes y habilidades para actuar ajustadamente. Las profesionales del Centro de Salud del Polígono Sur han desarrollado nuevos roles como instigadoras, mediadoras y abogadas de la salud sexual y reproductiva de las mujeres gitanas[28]. Han promovido relaciones entre las mujeres gitanas y los servicios de salud, han trabajado en la comunidad con los recursos disponibles de acuerdo con las características de sus usuarias, han identificado sus necesidades y han adaptado el programa de que disponían. Esto demuestra que las profesionales son agentes clave del cambio de la salud sexual y reproductiva de las mujeres gitanas, tanto en su propia organización como en la comunidad donde trabajan. Las profesionales del Centro de Salud del Polígono Sur han logrado mejorar la accesibilidad y la adherencia al programa, lo han convertido en un espacio seguro para las mujeres gitanas y han logrado asegurar su sostenibilidad en contextos de exclusión. El sistema debe cuidar y reconocer esta labor, y permitir a las profesionales influir en sus organizaciones, incorporar sus experiencias y necesidades en el diseño de programas, así como ofrecerles formación y apoyo para desarrollar su trabajo de la manera menos costosa para ellas y para las usuarias[29–31].

Adecuar los programas de salud sexual y reproductiva a las mujeres gitanas conlleva abordar asuntos de justicia reproductiva; esto es, promover en las usuarias el ejercicio de su derecho a mantener la autonomía del propio cuerpo, ser madres o no, y cuidar de su familia y de ellas mismas en comunidades seguras[33]. Esta concepción impulsará a las mujeres gitanas a cuestionarse mandatos de género impuestos y a adoptar una nueva concepción de su salud sexual y reproductiva, en la que el significado de ser mujer sea construido por ellas mismas desde la igualdad y las fortalezas de su cultura[7]. Esto supondrá la adquisición de control, influencia, relevancia y significado dentro de su comunidad y fuera de ella[32,33]. Los programas de salud sexual y reproductiva deben aprovechar el momento actual de cambios sociales liderados por mujeres gitanas, especialmente las más jóvenes[34,35]. Según la Organización Mundial de la Salud[13], el progreso real llegará cuando sean ellas mismas las que diseñen, implementen y evalúen los programas de salud sexual y reproductiva que les atañe. Es deber de las profesionales y de las instituciones acompañar y facilitar estos procesos[29].

En conclusión, el impacto en la salud sexual y reproductiva de las mujeres gitanas va a depender en buena medida de profesionales sensibles a la diversidad capaces de influir en sus organizaciones y en las mujeres sobre el derecho a su salud. Para ello, el compromiso de las instituciones y el respeto a la diversidad cultural y a los determinantes sociales de la salud deben ser los marcos de referencia desde los que se construyan las políticas y los programas de salud sexual y reproductiva[25]. La diseminación, la transferencia y la institucionalización de experiencias de éxito, como la que se presenta en este artículo, pueden contribuir a arrojar luz sobre este desafío.

¿Qué se sabe sobre el tema?

Se carece de evidencias que informen las guías, protocolos y programas de salud sexual y reproductiva dirigidos a mujeres gitanas en riesgo de exclusión, una prioridad en el componente de salud de la Estrategia Nacional de Inclusión de la Población Gitana en España.

¿Qué añade el estudio realizado a la literatura?

Describe las adaptaciones locales no institucionalizadas de un programa de planificación familiar centradas en captar y adherir a mujeres gitanas en riesgo de exclusión. Enfatiza el ajuste de políticas y programas a la salud sexual y reproductiva de las mujeres gitanas en exclusión, y a los esfuerzos que su implementación conlleva para los profesionales de la salud.

Editor responsable del artículo

Carlos Álvarez-Dardet.

Contribuciones de autoría

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Conflictos de intereses

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Apéndice D

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El Reto de la Equidad en las Políticas Sanitarias Dirigidas al Pueblo Gitano en España

The Challenge of Equity in Health Policies Aimed at the Roma Population in Spain

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Keywords*:* Roma people, community psychology, governance for health, wicked problem

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El Reto de la Equidad en las Políticas Sanitarias Dirigidas al Pueblo Gitano en España

Resumen

En este artículo abordamos la contribución de la psicología comunitaria en la formulación de políticas de salud pública transformadoras dirigidas al pueblo gitano. La brecha en salud entre la minoría gitana y el resto de la población en Europa, ha conducido a la Organización Internacional para las Migraciones a implementar el proyecto *Equi-Health*. Su finalidad es redefinir las políticas de salud dirigidas al pueblo gitano desde los principios de equidad y justicia social. En España, esto ha supuesto un proceso iterativo de cuatro fases: (1) encuadrar el problema, (2) construir capacidad de colaboración entre los agentes; (3) desarrollar conocimiento compartido, y (4) planificar acciones y fortalecer compromisos futuros. Las lecciones aprendidas de esta experiencia permiten: (1) visibilizar las fortalezas de la psicología comunitaria en la innovación de políticas de salud; (2) crear conciencia sobre nuestro compromiso con los grupos oprimidos, y (3) responder científicamente a la gobernanza de la salud.

The Challenge of Equity in Health Policies Aimed at the Roma Population in Spain

Abstract

In this paper we address the contribution of the community psychology to the formulation of transformative public health policies for the Roma. The gap in health between the Roma and the rest of population in Europe has led the International Organization for Migration to implement the Equi-Health Project. Its aim is to redefine public health policies addressed to the Roma from the values of equity and social justice. In Spain, it has entailed an iterative four stage process: (1) to frame the problem, (2) to build collaborative capacity among stakeholders; (3) to develop shared understanding, and (4) to plan future actions and strengthen commitments. The lessons learned from this experience allow to: (1) make the strengths of community psychology visible for the innovation of public health policies; (2) raise awareness of our commitment with oppressed groups; and (3) scientifically respond to governance for health.

Las inequidades en salud del pueblo gitano (PG) representan uno de los desafíos más complejos que afrontan actualmente las políticas públicas europeas de protección social. La evidencia muestra consistentemente que los indicadores de salud del PG son siempre peores que los del resto de la población debido a las precarias e injustas condiciones de vida que sufren (La Parra, 2009). En la actualidad, doce millones de personas gitanas viven en Europa, representando así la minoría étnica más numerosa y pobre—diez veces más pobre que el resto de la población (McKee, Balabanova & Steriu, 2007; Parekh & Rose, 2011). La mayoría tiene un bajo nivel educativo y vive en guetos o asentamientos; incluso cuando logran escapar del círculo de la pobreza, no consiguen mejorar su salud porque continúan atrapadas en el estigma y el silenciamiento (Fésus, Östlin, McKee & Ádány, 2012).

La ampliación de la Unión Europea con países con un alto porcentaje de población gitana (e.g., Rumanía y Bulgaria) fue la oportunidad para que en 2003 la Comisión Europea, el Banco Mundial y la *Open Society Foundations* organizaran la conferencia "*Roma in an expanding Europe: Challenges for the Future"* (Gitanos en una Europa en expansión: Desafíos para el futuro)[i]. El objetivo fue impulsar una Década para la Inclusión del PG (*Decade of Roma Inclusion 2005-2015*)[ii] que redujera de manera efectiva la brecha que los separaba del resto de la población en los ámbitos de educación, empleo, vivienda y salud. A pesar de los esfuerzos realizados, las condiciones de vida del PG en Europa siguieron empeorando y, en 2011, la Comisión Europea adoptó un marco que garantizase políticas nacionales de inclusión del PG (*EU Framework for National Roma Integration Strategies up to 2020).* A través de esta iniciativa, los estados miembros se comprometían a reforzar la legislación y apoyar a las autoridades regionales y locales para monitorear, compartir y fortalecer políticas integradoras. Además, se subrayó la necesidad de diseñar estrategias para comprometer activamente a todos los agentes sociales en procesos que adaptaran las políticas a las condiciones locales (European Commission, 2011).

Para asegurar el éxito de estos esfuerzos, la Organización Internacional para las Migraciones (OIM) ha impulsado el proyecto "*Equi Health*: Fomentando la provisión de asistencia sanitaria para migrantes, la población gitana y otros grupos vulnerables"[iii]. Su objetivo es garantizar el progreso en el acceso y adecuación de los servicios de salud al PG a través del fomento del diálogo y el desarrollo de capacidades entre múltiples agentes. Para ello, se propone redefinir las políticas de salud dirigidas al PG desde los valores y principios de la equidad y justicia social.

En este artículo presentamos el trabajo realizado por un equipo multidisciplinar nacido de la colaboración entre el Centro de Investigación y Acción Comunitaria de la Universidad de Sevilla (CESPYD) y la OIM para revisar la Estrategia Nacional para la Inclusión de la Población Gitana en España, en el área de salud (Vea el informe completo en http://equi-health.eea.iom.int/images/NRIS_Spain_final.pdf). La participación de profesionales de la psicología comunitaria en esta iniciativa ha permitido realzar el valor de esta disciplina en la gobernanza de la

salud. Los términos "políticas" y "planes" se emplean de manera indistinta (en inglés, *policy)* para referir un curso o principio de acción adoptado o propuesto por una institución, organización o individuo. En primer lugar, argumentamos el fracaso de las políticas dirigidas a superar las inequidades en la salud del PG—las cuales serán definidas como un problema retorcido o *wicked problem*—y cómo la psicología comunitaria puede ayudar a afrontarlas. A continuación presentamos y describimos el modelo que hemos desarrollado en España para redefinirlas y, finalmente, discutimos nuestros resultados con el fin de ayudar a futuros esfuerzos.

Problemas Retorcidos, Políticas Sanitarias para el Pueblo Gitano y Psicología Comunitaria

El fracaso de las políticas públicas que han tratado de corregir las inequidades en salud del PG puede explicarse desde su consideración como *problema retorcido* (en inglés, *wicked problem).* Acuñado por Rittel y Webber (1973), este término refiere a aquellos problemas que no pueden atenderse exitosamente con aproximaciones lineales y analíticas debido a su naturaleza cambiante e imprevisible, lo cual los hace muy resistentes a cualquier intento de solución.

En este sentido, las inequidades en salud del PG son un problema muy desestructurado, casi *líquido*. Su naturaleza y extensión depende de quién, cómo, cuándo y dónde se define, de manera que los esfuerzos por caracterizarlo y acotarlo fracasan e incluso transforman su naturaleza original. Acercamientos complementarios son incapaces de converger en una definición sólida que permita emprender acciones sostenibles. Su abordaje supone una *encrucijada* donde múltiples agentes rivalizan por hacer valer sus propias prioridades—siendo la escasa sinergia entre ellas la causa de su irrelevancia. Por ejemplo, está bien establecida la relación entre prácticas familiares machistas, abandono escolar precoz, maternidad adolescente y una precaria educación en salud sexual y reproductiva en mujeres gitanas (Logar, Rotar & Maksuti, 2015). Sin embargo, las políticas que se implementan perpetúan el ciclo de exclusión que pretenden combatir, ya que se enfocan en prevenir nuevos embarazos en madres multíparas en vez de promover una salud afectiva y sexual en adolescentes. Además, las inequidades en salud del PG tienen una *naturaleza implacable*, persistente, capaz de fagocitar todo intento de solución. Cambios que pueden resultar positivos para algunos grupos, son dañinos para otros. Por ejemplo, la mayor movilidad proporcionada por la ampliación del espacio Schengen[iv] no ha incrementado las oportunidades laborales del PG, sino que ha exacerbado el odio racial hacia ellos y ellas en el resto de países europeos (Human Rights First, 2008).

Como problema retorcido, las inequidades en salud del PG van a requerir que instituciones europeas, organizaciones de protección de los derechos humanos y civiles, y sistemas de protección nacionales y locales realicen un esfuerzo sostenido para asegurar planes públicos que las combatan permanentemente. Estos esfuerzos requieren un compromiso entre los agentes sociales para desarrollar un conocimiento compartido que vigile, corrija y prevenga su exacerbación y

agravamiento. Esto implica una visión pragmática del conocimiento (Weber & Khademian, 2008). Es decir, las políticas destinadas a combatir las inequidades en salud del PG deben sostenerse en la conexión entre el conocimiento tradicional—las *evidencias científicas*—y lo que el Pueblo Gitano hace en un contexto concreto—las *evidencias de la práctica*.

La misión de la psicología comunitaria es transformar realidades sociales desde la asunción de que están conformadas por políticas públicas que son mediadas por comunidades e individuos (Bishop, Vicary, Browne & Guard, 2009). Por tanto, es nuestra responsabilidad empoderar al PG en la promoción de políticas de salud orientadas a superar las inequidades que sufre. La psicología comunitaria ofrece el marco adecuado para que el PG: (1) adquiera visibilidad política, (2) tenga oportunidades para involucrarse y comprometerse activamente en las políticas que les atañe, (3) asegure la rendición de cuentas en su implementación, y (4) sensibilice a quienes planifican sobre los efectos que dichas políticas tienen sobre sus comunidades (Bishop et al., 2009; Nelson, 2013). A partir de estos principios y valores, Nelson (2013) ha acuñado el término *cambio político transformador* (CPT, *transformative policy change*) para referirse a cambios en la planificación pública que dan poder real a la ciudadanía para influir en las decisiones que afectan a sus vidas, al tiempo que incorpora la mejor evidencia científica disponible. Por tanto, los CPT exigen involucrar activa y horizontalmente a los agentes sociales a partir de los siguientes principios: (1) *Los contextos de diversidad son escenarios caracterizados por perspectivas plurales*. Ni hay un único modo de análisis de la realidad ni una única solución que pueda dar respuesta a las necesidades e intereses de todas las personas (Allen, Todd, Anderson, Davis, Javdani, & Bruehler, et al., 2013). (2) *Las relaciones entre los agentes implicados son elementos centrales en la ecología del problema.* Cualquier variación en la naturaleza, intensidad y autenticidad de dichas relaciones afecta a los procesos y resultados. (3) *Los CPT son procesos de movilización comunitaria* que comprometen personas, organizaciones e instituciones en la definición del problema, la identificación de soluciones y su implementación (García-Ramírez, Paloma, Suárez-Balcázar & Balcázar, 2009). (4) *Los CPT reconocen que todos los agentes involucrados son parte de la solución del problema*—o formarán parte del fracaso. Sus prioridades deben asegurarse en términos de beneficios y distribución equitativa de las responsabilidades y recursos.

Redefiniendo Políticas que Desafían las Inequidades en Salud del PG

A base de estos principios y tomando como guía la propuesta de Petersen, Janssen,

van der Sluijs, Risbey, Ravetz, Wardekker y colaboradores (2012) para manejar la incertidumbre que resulta de estos problemas retorcidos, establecimos un modelo de cuatro fases para redefinir las políticas públicas que desafían las inequidades en salud del PG en España (Ver Figura 1): (1) encuadrar el problema; (2) construir capacidad de colaboración entre los agentes; (3) desarrollar conocimiento compartido sobre el problema y sus posibles

Figura 1. Modelo de Cambios Transformadores de Políticas de Salud para el Pueblo Gitano

soluciones; y (4) planificar acciones y fortalecer compromisos futuros.

El Encuadre del Problema de las Inequidades en Salud del PG

Para encuadrar el problema de las inequidades en salud del PG se requiere conocer y analizar las definiciones existentes, las políticas que han tratado de resolverlas, las conexiones con otros problemas, así como hacer acopio de las evidencias, recursos disponibles y agentes sociales involucrados. A tal fin, constatamos que el reto de la Organización Mundial de la Salud para los próximos cinco años es eliminar la brecha de 10 años que separa la expectativa de vida del PG con la del resto de la población (WHO, 2014). Esta diferencia es atribuida a la alta prevalencia de enfermedades silentes, crónicas e infecciosas (e.g., diabetes, cardiovasculares, tuberculosis) y también mentales, las que nunca se diagnostican—o lo son en sus fases tardías (La Parra, 2009; WHO, 2014). La obesidad es considerada una epidemia entre las mujeres gitanas quienes, además, sufren importantes problemas de salud sexual y reproductiva como consecuencia de que muchas de ellas nunca acuden a consultas de ginecología o participan en programas de cribado de cáncer de mama y cérvix (Hajioff & McKee, 2000; La Parra, 2009; Parekh & Rose, 2011). Muchos niños y niñas no cumplen el calendario de vacunas y sufren problemas de desnutrición y malnutrición (La Parra, 2009; WHO, 2014). Estos ejemplos ilustran la permeabilidad e interacción de las inequidades en salud con otros graves

problemas del PG como el analfabetismo en personas adultas, el fracaso escolar, el desempleo a largo plazo (Brüggemann, 2012) y los déficits estructurales y de servicios en sus barrios (WHO, 2014). Todo ello pone de manifiesto que el fracaso en las políticas dirigidas a asegurar la integración y bienestar del PG fracasan como consecuencia de relaciones asimétricas de poder dentro del Sistema Público de Salud (SPS), de la sutil discriminación contra esta minoría entre los y las profesionales y la ciudadanía—que incluso llegan a sentir asco contra el Pueblo Gitano, deshumanizándolo (Dalsklev & Rønningsdalen Kunst, 2015; La Parra, 2009).

La Construcción de Capacidad de Colaboración entre los Agentes Implicados

Construir capacidad de colaboración entre múltiples agentes para desarrollar CPT requiere—además de recurrir a las mejores evidencias científicas—compromiso, cohesión y competencia de, y entre, todos y todas para definir una meta común, compartir una sólida hoja de ruta e implementarla (De Freitas, García-Ramírez, Aambø & Buttigieg, 2014; Nelson, 2013). Con estos propósitos, realizamos un proceso iterativo de tres componentes. El primero fue la puesta en marcha de un proceso abierto de creación de una coalición entre todos los agentes implicados en la salud del PG en Andalucía y Cataluña—las dos regiones españolas con más población gitana. Esta coalición estuvo compuesta por investigadores/as, planificadores/as de servicios, profesionales sanitarios, representantes sectoriales y de asociaciones gitanas, proveedores/as de agencias de servicios comunitarios y líderes de comunidad. El segundo componente consistió en un análisis participativo de los documentos "Criterios y Recomendaciones para Evaluar el Componente de Salud de las Estrategias Nacionales de Integración del PG" (WHO, 2012), las "Recomendaciones del Consejo de Europa para Asegurar Cuidados de Salud a la Población Migrante" (CoE, 2011) y los compromisos definidos en la Década para la Inclusión del PG[v]. El tercer componente consistió en un proceso recursivo de *scoping review* que incluyó literatura indexada y no indexada, así como planes y políticas regionales y locales, comprendiendo el período entre 2005 y 2013[vi].

La meta del trabajo colaborativo fue contrastar el grado de sensibilidad y equidad de las políticas de salud dirigidas al PG y proponer acciones para superar las inequidades. El documento guía para la evaluación de las políticas fue el Índice de Equidad de las Políticas Sanitarias para el PG (*Roma Health Integration Policy Index,* RHIPEX), que incluye una serie de indicadores agrupados en cuatro pilares (Ver Tabla 1): (1) titularidad del derecho a la asistencia sanitaria; (2) acceso al sistema de salud y sus servicios; (3) garantías sobre la calidad de los servicios; y (4) logro y sostenimiento de cambios.

El proceso recursivo de *scoping review* nos permitió acceder a las evidencias científicas, así como a políticas y planes vigentes. Para recoger las evidencias de las prácticas, la coalición fue la plataforma para realizar 33 entrevistas individuales y cuatro grupos focales: dos al inicio del proceso—en las que se definió la misión y se implementó el RHIPEX, y otras dos al final—en las que se decidió el plan de futuro. El documento final fue evaluado externamente en un proceso dirigido por la OIM. Posteriormente fue difundido entre todos los miembros de la coalición,

Dimensión	Indicador	Descripción
Titularidad del derecho a la asistencia sanitaria	Requisitos para la obtención del derecho	Requisitos formales e informales para la población gitana nacional y extranjera para acceder al sistema de salud y sus servicios. Incluye aspectos relacionados con el proceso de solicitud de la tarjeta sanitaria, de identificación y registro.
	Copagos	Sistema de pago que la población gitana tiene que realizar para tener acceso a la atención médica. Se examina la prevalencia de los pagos directos y los casos de exención (e.g., bajos ingresos o enfermedades crónicas).
	Cobertura	Lista de servicios a los que la población gitana tiene derecho. Distingue entre la cobertura para la población nacional y la extranjera.
Acceso al Sistema de salud y sus servicios	Barreras de accesibilidad	Barreras que impiden el acceso de la población gitana nacional y extranjera al Sistema Público de Salud. Éstas pueden estar relacionadas con las costumbres gitanas o derivadas del propio sistema y sus proveedores.
	Políticas destinadas a suprimir las barreras de accesibilidad	Políticas desarrolladas e implementadas por los planes locales, regionales o nacionales destinadas a hacer frente a las barreras de accesibilidad.
	Estrategias de adaptación para suprimir las barreras de accesibilidad	Acciones específicas desarrolladas por los proveedores de los centros de salud u ONGs para eliminar las barreras que dificultan el acceso de la población gitana a la asistencia sanitaria.
	Mediación en salud	Aspectos relacionados con las tareas de mediadores en salud que trabajan con población gitana.
Garantías sobre la calidad de los servicios	Inequidades en salud identificadas por la Estrategias Nacional	Inequidades descritas en el Plan Operacional 2014-2016.
	Políticas para hacer los servicios de salud más sensibles a la población gitana	Aspectos relacionados con la formación en competencia cultural de los proveedores de servicios.
	Estrategias de adaptación de los servicios de salud y los proveedores/as	Medidas adoptadas por los centros y los proveedores para adaptarse a las características y necesidades de la población gitana española y extranjera.
Logro y sostenimiento de cambios	El contexto político y económico de la NRIS	Capacidad del sistema de salud para lograr los objetivos del Plan Operacional de la Estrategia Nacional y cómo estos objetivos son modulados por las restricciones impuestas en el SPS.
	Asociacionismo, participación de la comunidad gitana nacional y extranjera	Relaciones entre la comunidad y gitana y las asociaciones, así como las relaciones de colaboración entre diferentes organizaciones y cómo estas contribuyen a la mejora de salud de la población gitana.
	Colaboración entre agentes implicados	Sinergias entre las diferentes organizaciones y cómo estas contribuyen a mejorar la salud y el bienestar de la comunidad gitana. Incluyen organismos locales, regionales y nacionales institucionales, instituciones sanitarias y académicas, asociaciones romaníes, organizaciones sociales y organizaciones no gubernamentales.
	Promoción de la acción intersectorial	Sinergias entre los diferentes programas destinados a promover y mejorar el uso de los servicios de salud en el marco de la Estrategia Nacional.

Tabla 1. Índice de Equidad de las Políticas Sanitarias para el Pueblo Gitano (RHIPEX): Dimensiones e indicadores.

las agencias de servicios y la comunidad gitana. En las siguientes subsecciones se presentan las principales fortalezas y debilidades de las políticas actuales y las propuestas de cambio que se adoptaron para el futuro.

El Conocimiento Compartido que Promueve CPT para la Salud del PG

Con el apoyo del software *Atlas.ti*, dos juezas independientes analizaron, sistematizaron y clasificaron la información disponible siguiendo un sistema de categorías elaborado a partir de los componentes del RHIPEX y otras categorías emergentes. El informe final siguió la estructura del RHIPEX, cuyos principales contenidos referimos a continuación.

Titularidad del derecho a la asistencia sanitaria

La actual política dirigida a superar las inequidades en salud del PG está diseñada sobre el principio de que la atención sanitaria en España es gratuita y universal, sin distinción de origen étnico, estatus social o permiso de residencia. Sin embargo, los recientes cambios legislativos (e.g., Real Decreto Ley 16/2012[vii]) han restringido este derecho a quienes contribuyen al Sistema Público de Salud a través de cotizaciones o a través de pago directo. Estos cambios han afectado a la salud del PG de manera excepcional ya que una parte importante de esta población está desempleada o trabaja sin cotizar a la seguridad social. Por otra parte, la adquisición de la tarjeta sanitaria—puerta de entrada al sistema—conlleva procedimientos burocráticos complejos y exigentes (e.g., documentar que se dispone de un domicilio fijo) que son barreras insalvables para que muchas personas y familias gitanas puedan hacer uso de sus derechos.

Acceso al sistema de salud y sus servicios

La actual política no ofrece suficiente atención a las principales barreras que encuentra el PG para acceder a los servicios de salud. Éstas están relacionadas con la cultura de cuidados del SPS, la falta de ajuste de sus canales de comunicación y las derivadas de la discriminación institucional. El SPS carece de sensibilidad cultural al no adaptar sus servicios a las necesidades de las minorías. Además, los protocolos de acceso requieren que las personas usuarias conozcan su compleja estructura interna y una jerga específica. El PG frecuentemente carece de estos conocimientos lo que le dificulta seguir los procedimientos estipulados y navegar por el sistema. Por su parte, el SPS emplea estrategias comunicativas generalmente escritas (e.g., *posters, websites*, folletos) que agrandan la brecha con el PG. Por tanto, estas barreras tienen un efecto multiplicador en la desconexión entre el PG y el sistema. Si en unas personas aumenta la falta de identificación con el SPS, el sistema y sus profesionales aumentan sus prejuicios sobre la imposibilidad de trabajar con ellos, resultando en un círculo perverso de discriminación.

Algunas estrategias se han implementado con el fin de superar estas barreras. Especialmente relevantes son los programas de mediación en salud financiados por los gobiernos regionales e implementados por organizaciones sociales o entidades subcontratadas. Estos programas buscan empoderar a las personas usuarias de etnia gitana promoviendo entre ellas el conocimiento de sus derechos y cómo navegar por el sistema. También se han ocupado de formar a quienes proveen servicios y en cooperar

con ellos y ellas para promover vías de acceso más amigables para el PG.

Garantías sobre la calidad de los servicios

La política de la Estrategia Nacional de Inclusión de la Población Gitana en España para garantizar la calidad de las prestaciones enfrenta tres importantes amenazas: (1) la carencia de medidas para ofrecer servicios al PG extranjero, (2) un planteamiento exclusivamente biomédico y (3) unos objetivos que no están formulados de manera interconectada ni integrada con el resto de políticas. A pesar de estas amenazas, se han realizado importantes esfuerzos que deben optimizarse. A nivel político destaca el afán por desarrollar planes regionales para formar a quienes proveen servicios de salud, elaborar guías sobre los principales problemas de salud y de acceso al SPS del PG y adaptar algunos servicios a sus necesidades. Algunos centros sanitarios han hecho esfuerzos por asegurar y cubrir sus necesidades más urgentes (e.g., planificación familiar, comunicación médico-paciente, prácticas religiosas). Estas adaptaciones las realizan proveedores/as que empeñan voluntariamente su tiempo en monitorizar y localizar a las personas usuarias, en ausencia de una política institucional que reconozca estos esfuerzos y asegure su continuidad.

Logro y sostenimiento de cambios

Las actuales políticas públicas establecen cómo fortalecer la participación del PG en el desarrollo de esas políticas y asegurar el trabajo intersectorial, multi-territorial y de colaboración institucional. Sin embargo, aunque las evidencias y agentes consultados apoyan estos objetivos, llaman la atención sobre diversas fuentes de incertidumbre. En primer lugar, el actual contexto político y económico está caracterizado por dramáticos recortes en los servicios de salud, además de educación y empleo. En segundo lugar, es notable la falta de compromiso por parte de las personas responsables de las políticas y la carencia de un sistema de rendición de cuentas que sea efectivo. En tercer lugar, el movimiento asociativo gitano vive actualmente una burocratización creciente y tiene importantes dificultades para representar a las nuevas comunidades gitanas y liderar sus desafíos. Estos fenómenos ocurren normalmente en conglomerados asociativos que rivalizan por obtener fondos, que deben mantener infraestructuras muy costosas y en las que la participación ciudadana es cada vez menor—e inexistente en el caso del PG extranjero. Y, por último, se pone de manifiesto la falta de trabajo intersectorial y la fragmentación actual entre las políticas que promueven la integración y el bienestar del PG.

Planificar Acciones y Fortalecer Compromisos Futuros

Los agentes de la coalición han subrayado que las políticas que desafíen las inequidades en salud del PG deben ser procesos de innovación guiados por los siguientes principios: (1) deben involucrar efectivamente a todos los agentes y asegurar que todas las voces son oídas (De Freitas et al., 2014); (2) asumir que las inequidades en salud del PG tienen una naturaleza interseccional, por lo que los CPT deben formularse desde una óptica intersectorial y sistémica; (3) la transparencia, permanente monitorización y rendición de cuentas deben articular los procesos de implementación de las políticas (Mittelmark, 2001); (4) el rol de las personas promotoras de las políticas debe ser el de constructoras de

capacidad de colaboración entre agentes, lo que implica actuar como instigadoras, mediadoras y abogadas de la salud del PG (Balcázar, Garate-Serafini & Keys, 2004); y (5) la eliminación del racismo institucional (Griffith, Mason, Yonas, Eng, Jeffries, Plihcik, et al., 2007).

Teniendo en cuenta estos principios, los CPT deben encaminarse a: (1) *Fortalecer la titularidad de la asistencia sanitaria* del PG nacional y extranjero, defendiendo y garantizando este derecho a través de mecanismos manejables para el PG y eliminando procedimientos administrativos injustos que—en la práctica—conculcan su derecho a la salud. (2) *Asegurar la accesibilidad al sistema de salud,* superando la idea de que equidad es sinónimo de igualdad en el acceso y estableciendo vías excepcionales que reconcilien los protocolos y prácticas con las situaciones de vulnerabilidad y movilidad que viven importantes sectores del PG. (3) *Garantizar la calidad de los servicios,* redefiniendo el propio sistema desde un enfoque comunitario de la salud, que priorice la promoción y la prevención, incluyendo al PG—extranjero y nacional—en los planes y estrategias del SPS, tanto como personas usuarias activas como promoviendo su formación como profesionales sanitarios. (4) A*segurar el logro y sostenibilidad de los cambios,* estableciendo mecanismos de fortalecimiento, revitalización y auto-crítica del movimiento asociativo gitano, mejorando el trabajo colaborativo entre los distintos actores, y promoviendo el liderazgo y participación del PG.

Los CPT pueden beneficiarse del uso de las nuevas tecnologías en el ámbito de salud pública. Basadas en el principio de "hacer para transformar" (Montero, 2006), estas metodologías (e.g., plataformas en línea) no solo permiten el empoderamiento y la alfabetización en salud del PG, sino que también son un medio para compartir recursos y conocimientos, así como crear redes y trabajo colaborativo entre múltiples agentes (Boyce, 2012; Suárez-Balcázar & García-Ramírez, 2003).

Discusión

Aunque los resultados de nuestro trabajo sólo pretenden ser de aplicación al contexto en el que se ha realizado, ciertas lecciones pueden ser de utilidad para esfuerzos similares en otros contextos. En primer lugar, nuestra experiencia resalta que los Cambios Políticos Transformadores son el resultado del empoderamiento de los agentes—es decir, su *capacitación para la gobernanza de la salud.* Esto implica la incorporación de la acción colectiva a la definición e implementación de las políticas, la redistribución de recursos económicos, intelectuales, normativos y políticos, así como la evaluación de sus efectos en la salud a través de un análisis de las relaciones de poder (Ottersen, Dasgupta, Blouin, Buss, Chongsuvivatwong, Frenk., et al., 2014). Por tanto, el PG se verá empoderado como legítimo agente político. Esto implica cambios en la manera de pensar sobre su salud y en su derecho a disfrutarla de acuerdo a sus valores y tradiciones, la adquisición de habilidades y capacidades para protagonizar su cuidado, así como a llevar a cabo acciones que la garanticen cuando esté amenazada (Balcázar et al., 2012; García-Ramírez, Hernández-Plaza, Albar, Luque-Ribelles & Suárez-Balcázar, et al., 2012).

En segundo lugar, este trabajo pone de manifiesto el papel del psicólogo y psicóloga comunitaria para *promover salud comunitaria y elaborar políticas*. Su papel debe ser entendido como el de

alguien que *construye capacidad de colaboración entre agentes*; alguien que tiene autoridad legal—capacidad reconocida por las demás personas—y que actúa investigando, innovando, comunicando, asesorando y fomentando alianzas. En definitiva, se convierte en un abogado o abogada social que sostiene su trabajo en la confianza y actúa como enlace entre todas las personas e instituciones involucradas (Balcázar, et al, 2004; Nelson, 2013).

En tercer lugar, también se ha puesto de manifiesto la importancia de las *organizaciones comunitarias como plataformas mediadoras*. Hacer valer estas estructuras como escenarios multiculturales empoderadores es un desafío para nuestro quehacer. Estas organizaciones deben ser referentes para las redes de múltiples agentes, generando procesos ágiles para redefinir sus metas, sus servicios y procesos organizacionales ante nuevos desafíos, promoviendo relaciones recíprocas y horizontales, fomentando la capacidad para desarrollar nuevos roles y regenerando el liderazgo en las estructuras (Suárez-Balcázar, Redmond, Kouba, Hellwig, Davis, Martinez, et al., 2007).

Finalmente, las difíciles circunstancias en las que vive el Pueblo Gitano deben conducir al psicólogo o psicóloga comunitaria—junto a todos los agentes sociales—a afirmar críticamente que la sociedad en su conjunto es responsable del sufrimiento que padece el PG, porque es causado por circunstancias que son evitables y que somos capaces de erradicar. En este sentido, debe incorporarse el *análisis de la responsabilidad de las inequidades*, erradicando la concepción falaz de que las desigualdades sociales matan cuando—en realidad—quienes matan son quienes se benefician de esas desigualdades (Navarro, 2013).

En definitiva, todos y todas tenemos la obligación de auxiliar al PG a vivir día a día, ayudarle a sobrevivir mientras encuentra significado, importancia y prosperidad en las comunidades (Prilleltensky, 2014). Estas tareas pueden parecer abrumadoras; sin embargo, los esfuerzos que estamos realizando en España con el auspicio de la OIM, son un ejemplo de cómo la ciudadanía puede comprometerse en la tarea de que el PG vea luz al final de un túnel de mil años de estigma.

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[i] Briefing Note Conference: "Roma in an Expanding Europe: Challenges for the Future" www-wds.worldbank.org/external/default/WDSContentServer/WDSP/IB/2003/07/24/000012009_20030724095242/Rendered/PDF/26415.pdf

[ii] Decade of Roma Inclusion 2005-2015 http://www.romadecade.org/

[iii] Proyecto Equi-Health, OIM http://equi-health.eea.iom.int/

[iv] "Territorio que comprende a aquellos Estados de la Unión Europea que han acordado la creación de un espacio común cuyos objetivos fundamentales son la supresión de fronteras entre estos países, la seguridad, la inmigración y la libre circulación de personas." http://www.interior.gob.es/web/servicios-al-ciudadano/extranjeria/acuerdo-de-schengen

[v] Decade of Roma Inclusion 2005-2015 www.romadecade.org

[vi] Los miembros de la coalición y los documentos que fueron revisados pueden ser consultados en el documento *Progress report of the Implementation of National Roma Integration Strategies in Spain* http://equi-health.eea.iom.int/images/NRIS_Spain_final.pdf

[vii] Real Decreto-ley 16/2012, de 20 de abril, de medidas urgentes para garantizar la sostenibilidad del Sistema Nacional de Salud y mejorar la calidad y seguridad de sus prestaciones. http://www.boe.es/diario_boe/txt.php?id=BOE-A-2012-5403

Vita

Marta Escobar Ballesta nació el 16 de octubre de 1988 en Sevilla. En 2012 se licenció en Psicología por la Universidad de Sevilla y se unió al grupo de investigación CESPYD, el Centro de Investigación y Acción Comunitaria de esta misma universidad. Posteriormente, cursó el Máster Oficial en Psicología de la Intervención Social y Comunitaria también en la Universidad de Sevilla, finalizando en 2013 con el Premio Extraordinario Fin de Estudios. Su interés por la investigación dentro del ámbito de la salud de minorías étnicas y otros grupos vulnerables la llevó a continuar su formación con el Máster Oficial en Migraciones Internacionales, Salud y Bienestar—obteniendo la titulación en 2014—y comenzar sus estudios de doctorado en Psicología en la Universidad de Sevilla. Durante estos años, la doctoranda ha participado y colaborado en numerosos proyectos de investigación financiados por la International Organization for Migration, la red COST y la Open Society Foundations, principalmente relacionados con la salud de la población gitana, su gobernanza y la evaluación de políticas de salud dirigidas a ella, así como con la adecuación de los servicios y sistemas de salud hacia la población migrante y refugiada. Esto le ha permitido diseminar sus resultados en conferencias nacionales e internacionales así como en revistas de investigación e informes científico-técnicos.

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